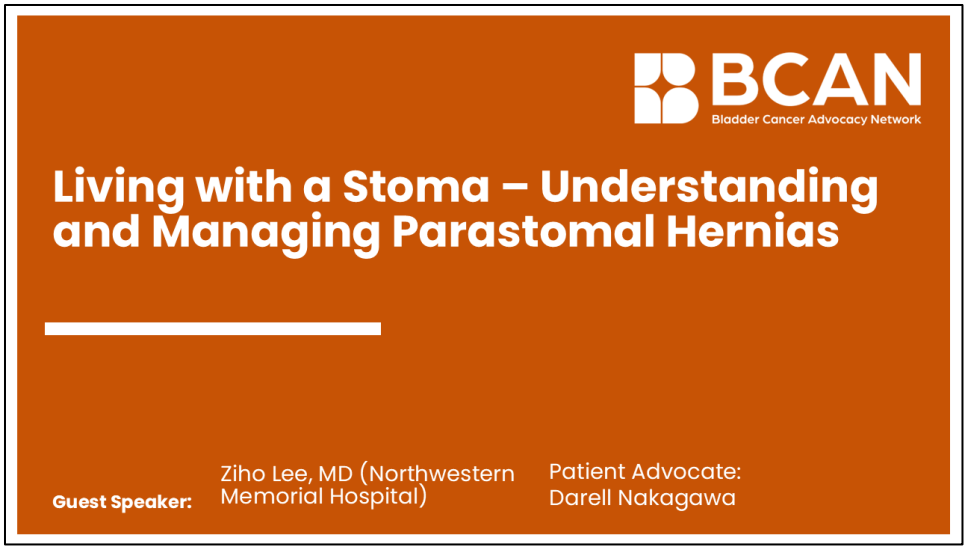

Patricia Rios:

So Darrell, thank you again for joining us today. As Dr. Lee mentioned, you're one of his patients. And having gone through one of those repairs yourself, you felt it was important for others to learn from your experience. So thank you for being here to share that with us. And I would like if it's okay for you to share, starting with your bladder cancer journey and then talking about your preparation and what was recovery like for you after this repair?

Darrell Nakagawa:

Great. Great. Thank you, Patricia. So my radical cystectomy was May 24th, 2017, so eight and a half years ago. And like everyone, I heard the news of, "Well, parastomal hernias recur so to hold off as long as possible to get it fixed." And I held off for just about eight years. And it was comfortable enough because there was minimal pain for me for most of the time. And there were some challenges in terms of finding the right wafer to fit the stoma and to fit my belly. As you can see, I'm a bit more robust than a normal fit person. In other words, I'm overweight, so prime suspect for a hernia. And around the seven-year mark, I began noticing more pain. It's when I saw gas became a problem, and that really did create more discomfort with my hernia. And Dr. Meeks, my urologist, and I had discussed getting the hernia fixed several times through my journey, and I'd even considered contacting the plastic surgeon, only we never connected.

But around, again, my annual visit at seven years, I was told about, there's this new doctor here at Northwestern, and he would refer me to him, and Dr. Lee would look at my hernia and see if that was something that he believed he could fix. And so he did finally contact me, and we scheduled a session, and we discussed having the hernia fixed.

And I said, This ... It made sense that it was kind of neat that it would be robotic and that recovery would be relatively easy. And so we scheduled it for a certain date, and then I realized that it was right before a big conference that I was going to be attending. So that was not going to be good timing because of the amount of walking and exertion that happens at that conference. So we reschedule it for another time, and it was actually perfect timing because there was another time that I was going to be traveling, but I had enough time to heal the operation and whatnot and be able to lift my bag up into the overhead bin.

In terms of preparing, his direction to me was, at a prior webinar we had with BCAN on parastomal hernia, that doctor had advocated doing some abdominal exercises, whereas Dr. Lee recommended not doing any. So that was like, "Oh, this is good. I don't have to go to the gym." And again, the nice thing was that it was day surgery as opposed to having to go through open surgery.

When my cystectomy happened, it was open surgery, and I don't know why the original urologist recommended open surgery versus robotic, but now I've had the opportunity to experience a full open surgery and then now the robotic. And now I would highly recommend robotic when possible. Why? Because again, it was that four millimeter opening as opposed to having to deal with the full open surgery, and that was a long and somewhat arduous recovery. It's also possibly a longer surgery. Dr. Lee can confirm that or deny that. But also the great thing was that, again, this is being done by a urologist who knows a lot of what's going on inside as opposed to just the plastic surgeon.

Also, healing was really easy because it was, rather than sutures, externally, it was just glue. So even showering and cleaning up was really simple. Clothes are fitting much easier. Changing of the wafer and pouch is much easier now, and I don't have to be concerned with some of the extras that I used before. I have continued, however, to use the Stealth Belt because I find that really helps supporting the pouch, especially when it's full. So I'm a huge advocate for the Stealth Belt. And post-surgery, there's still the normal recovery from anesthesia. My bowels took a few days to activate, so there was some time with that, but it was a really simple surgery in my mind, and recovery was really simple. And I have noticed that I feel stronger now and a bit more stable in even climbing stairs and whatnot.

So that's kind of why I said there's this newer fixing of the parastomal hernia that really gives us bladder cancer patients greater opportunity to fix some of the possible effects from our original cystectomy.

Patricia Rios:

Thank you, Darrell. Thank you for sharing your experience and being an advocate, not only for those who may be experiencing this, but for bladder cancer patients in general.

I heard the word belt a lot during the conversation, and so there were a lot of questions around belt as well. So I thought maybe we addressed those. Dr. Lee, you did talk about them about as a non-surgical technique for management. Are these hernia belts effective in preventing? Are there any specific anti-hernia support belts that you recommend, or are

there any tips on how to best use them? I know there's a lot of questions around belts, but as much as you can share with us.

Dr. Ziho Lee:

Yeah, so that's a great question, and that's one that we get asked a lot. Hernia belts, it's really surgeon dependent on who likes to use them. For me, I do not perform cystectomy and ileal conduit or neobladder and Indiana pouches for cancer, but I do it for reconstructive issues or complications from cancer like radiation and things of that nature. For me, I do the entire surgery all robotically. I do not use these belts routinely. And the reason is because sometimes patients, it's just hard for patients to do. It can be uncomfortable, especially when they're eating because you want that to be very nice and snug. Essentially what it is, it's a band that's Velcro strapped and you wrap it around your belly and there's usually a little plastic ring that kind of buttresses where your stoma is. And some patients can actually have pain there because of the plastic compression, but I typically don't recommend just routine use because I think sometimes it's a little more trouble than it's worth, and that's just my personal opinion.

I do know back in training, sometimes we had an abdominal binder that patients would wear for one to two weeks. To be honest with you, I'm not sure how much that actually helps in preventing. I think where I see the most utilization is perhaps a patient who is very hesitant to undergo surgery, who maybe has some nonspecific pain in the belly where the abdominal binder helps with the pain because sometimes with these hernias, if you push, you can push whatever contents are in there back out of the hernia. And what you're doing is it's just buttressing it. But remember, as soon as you take it off, when you're going to take a shower, you're going into a pool or you're getting change, the hernia's going to come right back in. And so it's really a temporary fix.

I do think that in the right situation, it's certainly useful as an adjunct. In my practice, just the way that it is, my practice is based on a lot of referrals from really all over the country. And so when people come and see me, they're usually like, "When can we do surgery," not about belts. So it's a little bit of a skewed, but I do think in the right situation, an abdominal belt could be useful for a lot of patients depending on what your goals are.

Patricia Rios:

Okay. Well, thank you for answering that. Darrell, your question about exercise and trying to minimize that after concern with the surgery, there were a lot of questions that were submitted in advance around exercise in general. And Dr. Lee, I was hoping you could speak to that and on whether there's certain exercise that patients should avoid doing if they have a hernia or are there any exercise they should be doing that helps strengthen the fascia muscle around stoma.

Dr. Ziho Lee:

That's a great question because my thought is that if you increase abdominal wall pressure, it could be pushing abdominal contents in that space. I think in theory, yes. But honestly, weight loss is very important for reducing hernias, not just parastomal hernias, and also just for general health. And so I never caution patients not to do certain exercises. And so my take would be to continue with the exercise. I wouldn't really tailor your exercises to anything, but weight loss also helps significantly because it just decreases the amount of pressure in your abdomen. And so that's a very important step that everyone can take that's obviously non-surgical that can improve other aspects of your life.

Patricia Rios:

Great, thanks. Darrell, I see you nodding your head. Anything you want to add?

Darrell Nakagawa:

No.

Patricia Rios:

Okay. Excellent. Let's see, there's a couple questions here around ... Sorry, I'm going through all of them. Dr. Lee, and Darrell also mentioned this, that there are many physicians, surgeons like you who perform these kinds of repairs. As you mentioned, most of them are plastic surgeons. And so how does one go about finding someone like you if they don't necessarily live close to Northwestern?

Dr. Ziho Lee:

That's a great question. In the urology space, there aren't many urologists who offer the surgery. Off the top of my head, there are really two surgeons who do this from a urology space, because a lot of times it's historically and traditionally it's been reserved for plastic surgeons or hernia doctors because urologists, we just don't do a lot of those procedures. I do have a fellowship program here at Northwestern, and my trainees, I graduated our first fellow last year. He does offer that in the LA area. He's at Cedars-Sinai. His name's Aurash Tavakolian, but it's hard because ... And this is why these educational events and when we meet up as urologists at conferences, dispersion and integration of ideas is so important because I think, again, all boats rise when the tide rises, it's one of those situations where it's about education and discussing these and having an honest discussion with ourselves, how can we best help our patients?

And like what Darrell was saying, that point about the ileal conduit, that's a very astute point where, yeah, I mean, plastic surgeons arguably fix this way more often. They fix hernias way more often than I do. But I know that when they're fixing something like this, and if there's any question about the conduit, I know I'm getting a call. For me, my job, I have a practice where I deal with complications from these stomas and conduits. And so I'm very familiar with the anatomy. And again, I'm not saying this to say, "Oh, this has to be the way to go. This is the

only option." For me, I find that this works very well for my practice and we've had a lot of very happy patients from it.

And I try to do a lot of educational stuff. We have a robotic reconstruction course just because this subject modality of robotic reconstruction too is still really much in its infancy. And that's why I did two fellowship trainings is because there was no fellowship at the time that would help me be competent in both areas in my opinion. And so I think as a field, we're really trying to help our patients the best we can. And I feel very fortunate to have learned from the people that I've learned from. But again, it's kind of like a team effort because it's the patients, it's having things like this, it's talking with other surgeons to really come up with solutions. And it's not wrong to do it with the plastic surgeon, that's how it's done at most places. And the plastic surgeon that I work with is one of the best surgeons I've ever seen.

And so it's one of those situations where I think you got to know what's right for you. And we're always welcoming to patients from far away. I do telephone conferences too. So patients from far away, we can just meet and talk and see if it's right for you and just have an open, honest discussion really, and because it may not be right for you. And so I think being honest with ourselves and really trying to do what's best for the patient is what really drives these decisions.