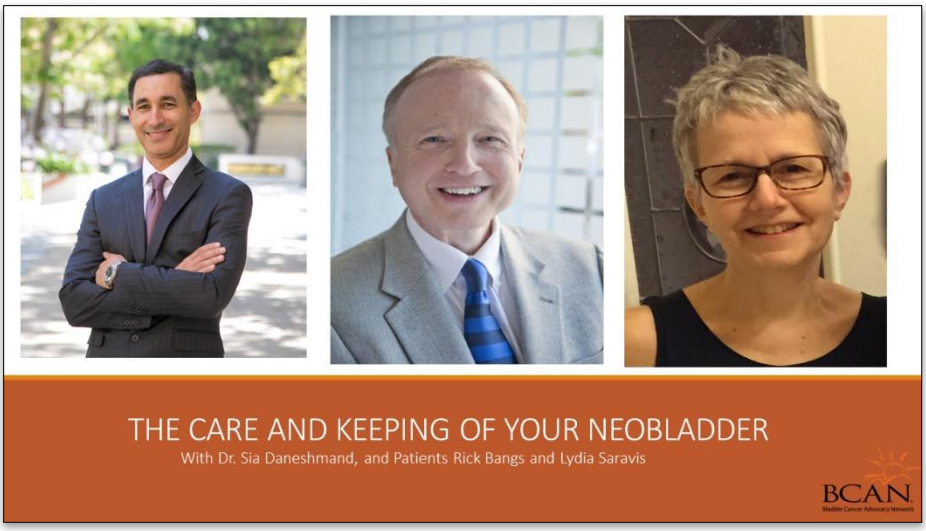

Stephanie Chisolm:

I know you've mentioned staying hydrated and some of the other things that you have learned over time. But the questions are really looking at does the mucus production, how much it's produced and does it decrease your go away over time? Does your diet affect that at all? Or is it just as much liquid as you have? How do you control the amount of mucus? Is there anything that you or Lydia has found that helps to limit the amount of mucus? Dr. Daneshmand, if you have any suggestions for folks.

Dr. Sia Daneshmand:

Yeah. I can just say some general a sense of that. The mucus comes from the intestinal tract producing this material that helps in digestion of food. So despite the fact that now urine's going through this, there are some changes within the lining that flatten out the absorptive capacity of the neobladder. It's still at the end of the day, it's ilium. And it produces mucus. So it'll decrease with time. It'll always be there but probably about a year out or so you'll notice there's very little of it that it's not an issue for most patients. Production, I have heard many patients say, when I'm dehydrated, I get more thicker mucus, or for some reason I have this meal and I produced more. Well, this is not connected to your intestinal tract, so it's completely separate, it doesn't traverse through the intestinal tract. And most likely those foods and all that has to do with hydration level and less to do with what you're eating.

Stephanie Chisolm:

That's a really good point. Lydia and Rick, did you have any suggestions that you've used that have helped you control this as an issue?

Rick Bangs:

Yeah. I was going to say, for me, I'm 14 years out, so I have the 2006 model year. After I first came out of surgery, it literally was like egg drop soup, and I hope nobody's eating as we're talking. And so you can imagine that to me that was a lot of mucus. I don't notice, I barely noticed the mucus anymore. I mean, it's such a small amount. It does tend to empty first, but I don't really notice anything, but I do keep well hydrated. So maybe if I didn't keep hydrated that I would have more of an issue, but I barely notice it anymore.

Stephanie Chisolm:

Okay. Lydia, anything else before we switch to the next question?

Lydia Saravis:

No, I would agree that it has decreased over time and I do still have noticeable, but it does correlate with hydration and I thought perhaps certain foods or medications, but again, that might be a correlation of hydration.

Stephanie Chisolm:

Right. Okay. Should neobladder patients avoid contact sports? Similar types of activities, really heavy physical activities. Is that a problem?

Rick Bangs:

No. The short answer is no. Once everything is healed there's no limitation as far as activities go. The abdominal muscles in front of the neobladder are fairly strong that protect the neobladder the same way. And plus it's your body. It's very highly flexible inside. So if you do sustain damage or get into an accident or anything, it pretty much acts the same way as the bladder does. It is a bit thinner, so if you get into a major accident, the chances of rupture are slightly higher, but that's an extremely rare situation.

Stephanie Chisolm:

Can a neobladder be resized if it stretches too large? Is that a problem that you ever had Dr. Daneshmand?

Dr. Sia Daneshmand:

Yeah, absolutely. So there are patients who don't realize it and their neobladder gets really stretched out there. It can, I've seen up to two liters in a neobladder which was a tremendous amount. It turns out after a while it actually goes back to fairly normal size. It doesn't stretch to that level and then stay stretched and become a sloppy bag. So there's no need to decrease the size of neobladder. I have had one situation where I had to increase the size of the neobladder because for whatever reason, it had really shrunk down. This was not one done by myself. It was from outside. And I still to this day, don't understand. I suspect that they didn't take long enough segment of the ileum for it to stretch. But so we increased the size of that neobladder, but the other way around, we don't need to do that.

Stephanie Chisolm:

So the follow-up question, what anatomical changes lead to increased neobladder capacity over time, stretching of bowel tissue, the bowel wall muscle relaxation, etc... Are there any anatomical changes that can impact neobladder capacity?

Dr. Sia Daneshmand:

Yeah, so basically the bowel stretches, the bowel wall stretches in a normal, as it holds more and more. It's one of those parts of the body that actually will stretch naturally. And just like the uterus stretches with pregnancy, there's certain parts of the body that can be stretched. The skin can be stretched. And so there's actual duplication of the cells and replication to the point where it does the work and it

remains the most important thing is that it remains a low pressure reservoir. That's what it's meant to be when it's in fact, a lower pressure than the normal bladder is.

Stephanie Chisolm:

Okay. A quick question here that came in a little bit earlier, should I be finding a primary care physician and, or urologist that's familiar with neobladder since this individual's regular PCP is not really familiar with that? You think that's an important factor that they need to be more familiar with the neobladder?

Dr. Sia Daneshmand:

Yeah. I think it's important for a couple of reasons. Like Rick mentioned and Lydia had mentioned it, there are longterm changes that can occur that if you don't notice them over time, that things will happen. Things like B12 deficiency and the bicarbonate level, which is of critical importance. I think there's another question here about metabolic acidosis. It's actually somewhat frequented and the more renal dysfunction you have, the more chance of having a metabolic acidosis. So many people don't recognize this. They look at the sodium, they look at the potassium, they don't really look at the CO2 levels normally. And if this is chronically low, then the patients can develop bone loss and over a five year period of time lead to fractures and things like that. So I think it is important.

Other things we see on the other side is, routinely, primary care physicians will do a urinalysis on a patient with a neobladder, which invariably leads to white cells and red cells out of range of normal. And they will call the patient or their nurse will call and say, "You have an infection." Well, and they get treated with antibiotics unnecessarily, and the patient is completely asymptomatic and absolutely does not have an infection and really should not be treated with antibiotics.

So we have to reeducate the patients and the primary care physicians that, don't do a urinalysis on a patient with a neobladder or any diversion for that matter, because what you see on an urinalysis is completely irrelevant. This is not a bladder urine, this a neobladder urine. So you're going to see lots of things. So I think it's important that patients educate themselves also. And when someone's checking their urine, ask, "What are you checking for?" Because that's just a part of routine, primary care annual sort of physical.

Stephanie Chisolm:

So really it does help to have that owner's manual. If you were going to go with this car analogy. So you can point this out and say, "Hey, look, these are some things as my primary care provider, you should recognize, and you should know. And if you have any questions, make sure that you let me know so I can get the answers for you from my urologist who did my surgery." I think that's a good idea.

Dr. Sia Daneshmand:

Exactly.

Stephanie Chisolm:

So going on that car analogy, there was a question about the warranties. What's the average lifespan of a neobladder?

Dr. Sia Daneshmand:

Rick is, what, 14 years out now, Rick?

Rick Bangs:

That's right.

Dr. Sia Daneshmand:

So, the expiration date is 15 years. So you're going to have to go in for the new model. No such thing. Actually, one of the few things in life that gets better with age, meaning this is completely part of your own body. Your body recognizes that the issue, it changes in a good way usually. And then there's really no expiration dates on neobladders. It just is completely a part of your own body. So lifelong warranty here.

Stephanie Chisolm:

Excellent. So, like a good Volvo that can go for a few hundred thousand miles. You can just keep going. Which is good. So talk a little bit, if you don't mind about kidney and bladder stones. How do they develop, how do you get rid of them? How do you avoid them?

Dr. Sia Daneshmand:

Okay, that's a good question. And I think again, Rick had a good tip there about drinking lots of water. So having a neobladder, doesn't put you at increased risk of developing kidney stones, per se. If you were a patient who was prone to developing kidney stones, you'll develop them again. Also poor emptying. So if you do have small little kidney stones and you're not emptying your neobladder well, then it can stay there and result in a bigger and bigger stone.

Now, those are the types of things we check on your six month visits, annual visits, we're checking those for exactly those things. They're not common. Neobladder stones are fairly uncommon. The neobladder, eventually, that the stones come out on their own.

If you do develop a kidney stone or a neobladder stone, they're treated the same way we do the normal kidney stones, except it is more difficult to get up there. As I showed you the pictures of how this is reconstructed, the ureters are a little bit further from our reach and difficult because you've got this twisted turning segment of bowel that flops to one side or the other, and it's harder to access the upper track. So it becomes a little bit more challenge and you need to have really good endourologist who's versed at treating kidney stones specifically in neobladder patients.

The shock wave lithotripsy is the same. Some of these stones are shot. Neobladder stones are very easy to manage. We just look in there, grab it, and pull it out if it's small. If it's really large, we sit there and laser it. And again, those are unusual. They're a little bit more common with the Indiana pouches because invariably, those don't empty completely and there are dependent portions of it that hold the urine and develop stones. So a little bit more common in the continent cutaneous diversions, or Indiana pouch is one of them.

Stephanie Chisolm:

Great. This is a good suggestion and information. So if continence can't be achieved after an appropriate period of time, is there anything that can be done surgically or nonsurgically to correct this problem? Dr. Daneshmand, do you work with a pelvic floor physical therapist at all? Is there any process that you can do that might help someone to have better control of their bladder once they have that neobladder?

Dr. Sia Daneshmand:

Yeah, that's a great question. And Lydia brought this up to make sure that your center has a physical therapy program or pelvic floor rehab program, pelvic floor physical therapy. Many of them are versed in getting patients post-prostatectomy backs to continence, and that there's more and more science behind pelvic floor rehabilitation.

So absolutely we have one, they're very well versed in neobladders specifically and actually Eileen Johnson. Who's one of our leads at our center, wrote the chapter for me in that book that I showed you. So that's one. The next question is what if I've done all that, it's been a year I'm still leaking during the day, or I have really bad incontinence at night and I catheterize and I'm just not happy?

Is there something you can do? And the answer is absolutely, there's an artificial urinary sphincter that can be placed, that goes around the urethra for men only unfortunately. Just because of anatomical limitations in women. So men would then press and squeeze a button in their scrotum. And this would allow the valve to open and allow the urine to expel from your neobladder. And then it automatically sort of closes. So they essentially become completely continent. Now it's not as simple as I say, because the surgery really has to be done by absolute expert that the bladder's not in the right place. The prostate has been removed. The anatomy is different, so they have to be very, very familiar with placing this artificial urinary sphincter. Absolutely has to be done in a center that is very, very well versed in this.

Stephanie Chisolm:

Okay, thank you. Does having bilateral nerve sparing radical cystectomy technique, enhance continence in addition enhancing possible erectile function in men?

Dr. Sia Daneshmand:

Oh, wow. That is a very good question. So erectile function, for sure, there's no question. Those nerves are controlling erectile function. So when we do a nerve sparing operation, we are trying to preserve erectile function in men. Let me just mention also in women that there are different kinds of nerves on the side or the lateral aspect of the vagina that are also involved in sexual function. And we try to now more and more preserve those nerves in women who are sexually active. So the question is, does nerve sparing alter or improve continence when you do a nerve sparing operation? It's a tough question to answer. We try to answer that question.

It seemed like when we looked back at our nerve sparing approaches, that the answer was yes. Nerve sparing approaches did improve continence, but the problem with that statistic is that we tended to do the nerve sparing on the younger patients. So, before I showed you older patients of similar continence as the younger one, but this is called the confounding variables. So the short answer is we think so I can't tell you a hundred percent that that does anything. So do we try to do a nerve sparing approach on a patient who already has erectile dysfunction for continence? Short answers is recently, yes. I think it probably helps, but we don't know for sure. They are different nerves that actually control continence and the urethral sphincter mechanisms. So whether there's some contribution there we're not exactly sure.

Stephanie Chisolm:

Okay. Dr. Daneshmand there's a question that's follow up to your artificial urinary sphincter question. What percentage of patients undergo the artificial urinary sphincter implantation for incontinence after having a neobladder? I know you mentioned that you have to go to somebody who really knows what they're doing to get it installed properly.

Dr. Sia Daneshmand:

Very, very few.

Stephanie Chisolm:

When I take your high end vehicle to the mechanic on the corner, you want to go to somebody that knows what your engine is all about. So what is the percentage?

Dr. Sia Daneshmand:

Yeah, so it's very, very low. I would say probably it's got to be less than 5%. And the reason is, we offer it to the patients and they ask us, is there something that can be done? We say, yeah, physical therapy. Yes, I did that. Anything else? We talk about surgery. They say, "No, I don't want surgery." And really, it's not that bad. I leaked a little bit at night. And most of the time, there are also other behavioral changes such as, again, Rick mentioned, changing your habits of how and when you drink fluids at night that affects what you do. What happens at night as well. So if all those fail then you go to the artificial unisphincter, but yet again, very few people have that operation.

Stephanie Chisolm:

This is a question that might be best for Lydia and Rick, but Dr. Daneshmand you can weigh in as well, how can neobladder patients who are still incontinent go swimming? It is summertime, so that might be a very relevant question for somebody. Is there any concern about, say swimming in the lake or a pool or whatever, if you have incontinence with a neobladder.

Rick Bangs:

I'm not sure how to answer that.

Dr. Sia Daneshmand:

I would say kids pee in the pool all the time, so don't worry about it.

Rick Bangs:

That's where I was going. I was like you can swim in your diapers and wear a guard, I mean ...

Dr. Sia Daneshmand:

You don't wear a guard. It gets messy. I think if you're a slightly incontinent then it's fine. If it's a big pool.

Stephanie Chisolm:

Well, a common thread on some of these questions is really just looking at what is an average target water volume to stay well hydrated and not overtax your neobladder?

Dr. Sia Daneshmand:

So, you constantly hear this eight glasses of water a day, and that's the general recommendation. In the beginning, we really stress hydration because they're are all kinds of changes going on. You really need to stay hydrated in the beginning. And the beginning means the first three months after surgery, once

everything is settled, six months later, a year later, it's not a plant. You don't need to keep watering it, it functions the same way.

If you notice thicker mucus, or you're developing multiple urinary tract infections, because your urine is so concentrated and you have mucus build up, then yeah, you need to drink more water. But if everything's functioning fine, you're doing well, you don't have stones, you don't have kidney infections or urinary infections, then the general recommendation is as with everybody else, eight glasses of water a day.

Stephanie Chisolm:

Okay, great. This is a question for Dr. Daneshmand, it's kind of combination of two questions. So there's no remedy for females who cannot achieve satisfactory continence after a year. And then one of the women on the call asked about having any urethral bulking agents to help with incontinence. Does it block mucus? Is that even a consideration for women since there's no little gadget that they can use?

Dr. Sia Daneshmand:

Great, excellent question. The answer is, yes. Let me elaborate because this is important. So, let's say women, after one year or one and a half years, they've done everything and they have significant incontinence and they say, "What can you do? I still want to keep my neobladder, but I'm very unhappy."

The answer is twofold. One is yes, absolutely. We can do urethral bulking agents. Imagine collagen, but not collagen. We could use something else. Somebody mentioned coaptite, it's just another agent that we use to bulk up the urethra. The results are somewhat mixed. Meaning, there's not enough experience with it.

I'm not talking surgical experience. I mean, enough data to show the improvement in continence. I have done it. Some have gotten better. Some have had no difference. It's worthwhile because it's such an easy procedure that we can do under minimal IV sedation. And it takes probably 15 to 20 minutes to do. It's very easy. So I think it's worth a try.

The problem with the female urethra is very short. And if someone wants to be completely continent, we can certainly do that with something called a sling, which is a surgery we do, where my colleagues do for female incontinence. The problem is because when the neobladder ... the neobladder's a low pressure system, it won't squeeze out the urine and now you'll go the other way. You'll go from leaking to being completely continent and not being able to urinate and needing to self-catheterize.

So we offer that to women and we say, "Well, we can put up a sling, it'll make you completely continent, no more pads. However, you do need to catheterize." And very, very few women go for it. That's the lesser of two evils, whichever. So it's very hard to control the tightness of that sling so that it's just right so you're not leaking and you don't need to catheterize. It's nearly impossible.

Stephanie Chisolm:

Okay, great. Thank you. There's a couple of questions that have come in regarding hernias. Are hernias more likely to occur? Are there special activities that should be avoided to reduce the risk of having a hernia and does having incisional hernias affect the working of a neobladder?

Dr. Sia Daneshmand:

No. No concern at all about ... Hernia is a very common after any kind of surgery and then cystectomy and neobladder or any other diversion is not immune to it. So absolutely. It's just one of those things

that happens over time as the muscles get weaker and they stretch out developing a hernia. So it's not a big deal. However, if it is a large hernia or if it's in the lower part of the abdomen, I would really recommend you talk to your urologist if they're comfortable fixing it themselves, or having them be involved with it with the repair because general surgeons who have done many, many of these hernias, but are not familiar with a neobladder being in the abdomen. If they get inside the abdomen and start to mess around down there, they will absolutely not know where the neobladder's located. And it would be an absolute disaster if they get into it. So just word of caution, getting the large ones fixed.

Stephanie Chisolm:

Okay, great. Thank you. And just a follow-up question on the urethral bulking agents. The concern about additional mucus blockage because of this bulking agent. Is that something that you've seen when you've given this treatment to some women?

Dr. Sia Daneshmand:

Not really. No, the mucus still comes out.

Stephanie Chisolm:

Okay. Well we have time for just maybe one more question, there's a lot of chatter on the BCAN Inspire site talking about prostate capsule sparing techniques for radical cystectomy in order to enhance continence. Is there data that shows that this enhances it? Does it diminish the oncologic effectiveness of a radical cystectomy because they're not taking out the prostate or doing it in a different manner? Is there anything that we should be aware of as a patient community in looking at that?

Dr. Sia Daneshmand:

So that's an excellent question. And it's almost like a question I would get at a scientific meeting from my own colleagues. So, I think I see that question right there, and absolutely it enhances continence. There's no question that if you spare the capsule and don't go right up to the edge, whether you're getting closer and closer to the urethral sphincter mechanism, that you're going to have near perfect continence, actually. If it's just the prostate capsule sparing.

The concern is twofold. One is yes, it diminishes the oncological effectiveness, although there are a couple of studies from Germany that show that's not the case. We, in the US and other parts of the world, have not adopted this technique because we do have significant concern about the oncological safety of leaving parts of the prostate behind where urothelial carcinoma or bladder cancer can invade. Once it does invade, it's absolutely not curable. It's not like we can go through surgery and just take this part out.

Usually it metastasizes, it's nasty, there's no boundaries to it. So that's the problem, it's a balance. I have done complete prostate sparing surgery where we spared the entire prostate. But those are very, very selected cases on very young patients or patients who don't have bladder cancer, urothelial cancer of the bladder, but they have sarcomas or other such cancers that don't affect the urothelium or the inner lining of the prostate.

Stephanie Chisolm:

Okay. Well, this has been incredibly informative. I greatly appreciate all of your expertise, both with performing neobladder surgery and in the living and care and keeping of these neobladders.

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