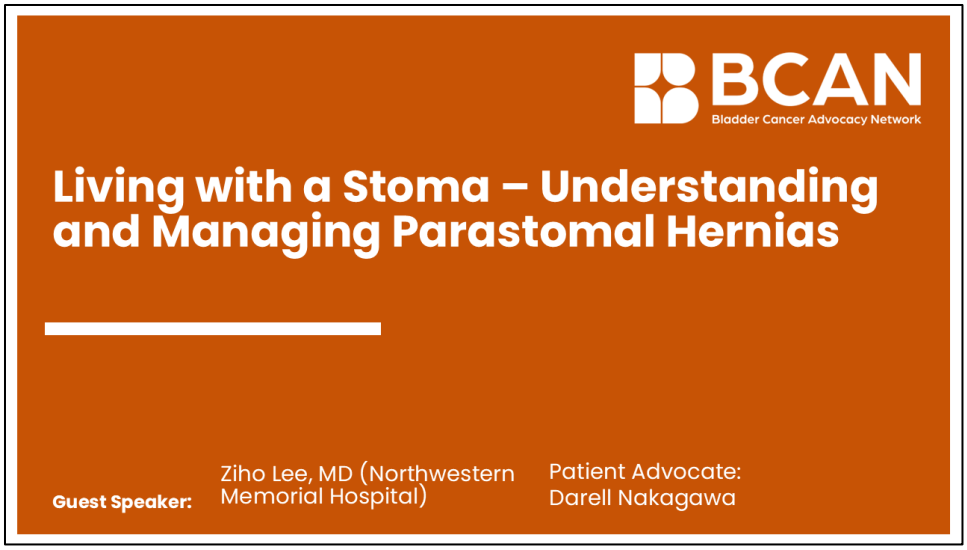


Patricia Rios:

Welcome to the Bladder Cancer Advocacy Network Patient Inside Webinar Series. My name is Patricia Rios, and I am the director of education and advocacy and your host for today's webinar on Living with a Stoma: Understanding and Managing Parastomal Hernias.

Today, I'm joined by two extraordinary speakers. But before I introduce you, let me tell you a little bit about today's topic. For many bladder cancer patients, a radical cystectomy or removal of the bladder may involve creating a stoma, an opening on the abdomen that allows urine to pass into an ostomy pouch. One possible complication after the surgery is the development of a parastomal hernia, which is a bulge or swelling around the stoma that occurs when abdominal tissue pushes through weakened muscle.

In this webinar, Dr. Ziho Lee will explain risks, options, and ways to maintain quality of life, whether you're newly adjusting to life with a stoma or have lived with one for years. Dr. Lee is a reconstructive urologist at Northwestern University. He completed his general surgery internship and urology residence at Temple University. He then went on to complete a fellowship in advanced robotic urologic oncology and reconstruction at Temple University and a fellowship in urologic trauma and reconstruction at the University of Washington.

Dr. Lee has a particular interest in robotic reconstruction of the upper and lower urinary tracts. Joining Dr. Lee is his patient, Darrell Nakagawa, who will share his real world experiences and insights with his repair. Darrell is a very active patient advocate. He's active with several organizations, including BCAN. He's a bladder patient advocate for the SWOG Cancer Research Network, one of the five national clinical trial networks community organizations. He leads the BCAN Chicago chapter and has worked with the Walk to End Bladder Cancer Since 2020 on both local and national level. A renaissance man, Darrell, has diverse interests and passions. He's a champion for diversity and inclusion and is active educating consumers on

different wines from across the globe. So we will hear from Darrell right after Dr. Lee's presentation.

Now, without further ado, I am going to hand over the screen to Dr. Lee for today's webinar on Living with a Stoma: Understanding and Managing Parastomal Hernias. Dr. Lee, thank you so much for joining us. The screen is all yours.

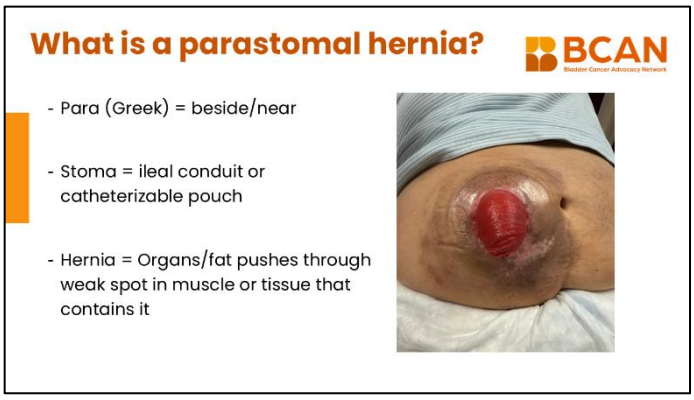
Dr. Ziho Lee:

Perfect. Well, thank you, Patricia, for the warm welcome and Darrell and Allison and Patricia for the kind invitation to give this talk today. It is an issue that I'm very passionate about, and I'm going to share my screen here. It really is an honor to be speaking for the Bladder Cancer Advocacy Network. I think patient engagement, especially things like this and educational seminars are extremely important, not only to increase education on potential issues, but also it just empowers patients and clinicians to make informed decisions and really kind of affect people's lives, so I really appreciate the invitation.

So I'm going to be talking about parastomal hernias.

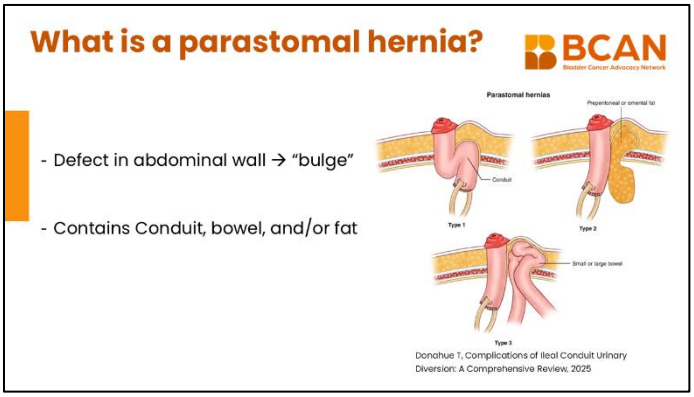
Dr. Ziho Lee:

When I start, I always like to ask the question, what is a parastomal hernia? And so if we go to the actual Greek origin of para, it means beside or near. Essentially what it is, is ... And the stoma obviously is an ileal conduit or a catheterizable pouch. Some patients may have Indiana pouches or anything where you can have an opening on the abdominal wall that allows access to urinary drainage.



So a parastomal hernia, essentially what it is when organs or fat push through a weak spot in the muscle or tissue that contains it. And so if we see this picture here, we see a stoma that's protuberant, and this is where urine will flow out of. And what's happening is around the stoma, there could be a little defect or a hernia where organs and fat can push through. And we'll talk about why this is a problem and certain risk factors that can cause this.

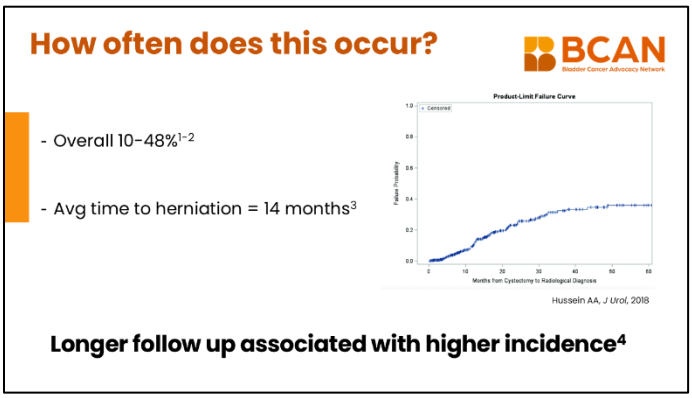
Dr. Ziho Lee:



So what is a parastomal hernia? Again, so if we look at it from more of a anatomic level, not just from a clinical picture level, what we see here is this is the stoma that we previously saw right, going through the abdominal wall. So this yellow portion is abdominal fat, this is abdominal muscle. And then these white layers here are layers called fascia. This is a tight band that helps keep all of our tissues kind of in on the inside. And what a parastomal hernia is, is when there's a defect along this fascia or this tight band that keeps all the tissue in. What happens is you can have herniation of a conduit. So the actual conduit itself can herniate through, which can kink the conduit and impair urinary drainage. We can also have fat or omentum. Omentum is a big body of fat that comes off the stomach, but having kind of fat contents in there can sometimes cause some pain or discomfort.

Or in the worst case scenario, you can have intestine. So you can have other small or large intestines that get trapped in the hernia. And you can actually have significant complications related to this, even more so than pain. What can happen is that the bowel can get stuck and essentially it can't get out. And what's happening is that it'll start swelling up and portions of the bowel can actually become necrotic or incarcerated, and that piece of bowel can die off and that becomes a surgical emergency.

Dr. Ziho Lee:

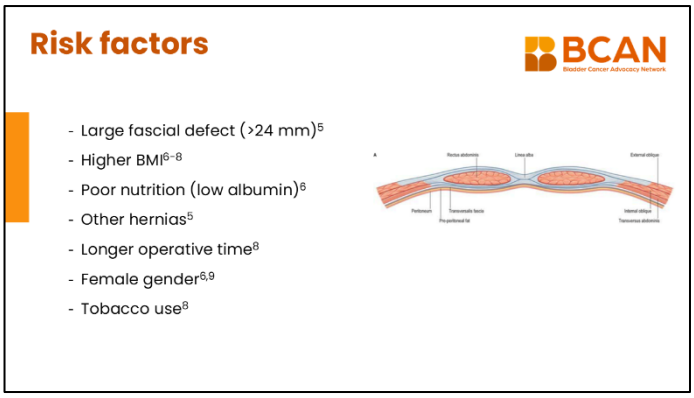


And so when we ask the question, how often does this occur? The exact rate is unclear. And the reason for this is because all these studies have variable numbers of patients, different levels of experience, and also different levels of follow-up. But what we can all agree on is that if we look at this graph, what this graph is showing is that on the X-axis here, it's months from cystectomy, and so it's time after your ileal conduit formation, and then the Y-axis is how likely is this to occur?

And we can see here as time goes on and on and on, you just have a higher and higher risk of this actually occurring. And so overall in the literature, the rates can be up to 50%. So this is not uncommon and it can actually be quite common. Additionally, the average time to herniation is about 14 months after the surgery. And so this is some food for thought because the longer you have this conduit for, and as we know, our bladder cancer survivors are living

longer lives after their initial surgery, you can see that sometimes up to 50% can have this issue. And so longer follow-up, so the longer you have this, it's associated with higher incidence of this parastomal hernia.

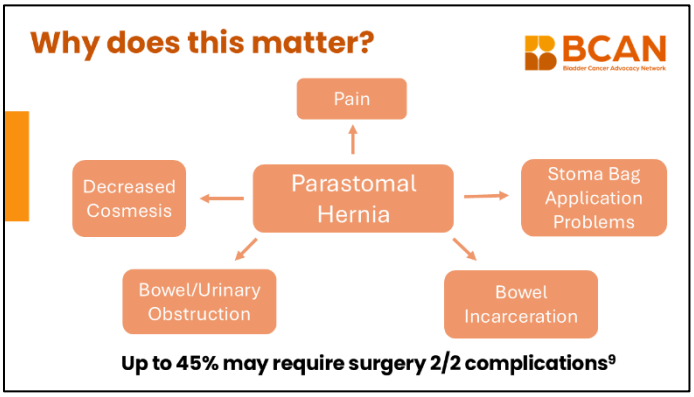
Dr. Ziho Lee:



And so what are the major risk factors? So I'm going to go into little details and just summarizing when this can happen. No one knows exactly why. There's not one reason why this may happen, but one is a fascial defect that's greater than 24 millimeters, so about 2.4 centimeters. So if we see here, this is a cross-sectional image of an abdominal wall. We could see the muscle here, these pink structures here are the muscles. And this white layer, as we were talking about, is the fascia. Again, the fascia is this tight band. So it keeps all our internal organs in and tight in the abdominal cavity. It's why a lot of times you don't have hernias, but when you have hernias, that's when you have a defect in the fascia. So when we make the ileal conduit or we make a stoma at the time of surgery, we have to make a small hole within the abdominal wall so we can bring up that stoma to allow the urine to drain to the outside.

And sometimes we find that when the hole is made very large, we can have an increased risk for these parastomal hernias. Additionally, patients with higher BMIs are at higher risk, patients with poor nutrition, patients with other hernias or history of hernias, maybe you have a hernia around your belly button or a hernia in your groin. So patients with a history of hernias, they're just predisposed to more hernias. Additionally, patients who have a long operative time also have an increased risk, female gender, and also tobacco use. So those are some risk factors. It's not like any one of these will definitively cause a hernia, but when we go back and look at the data, these factors are most closely associated with the formation of a parastomal hernia.

Dr. Ziho Lee:



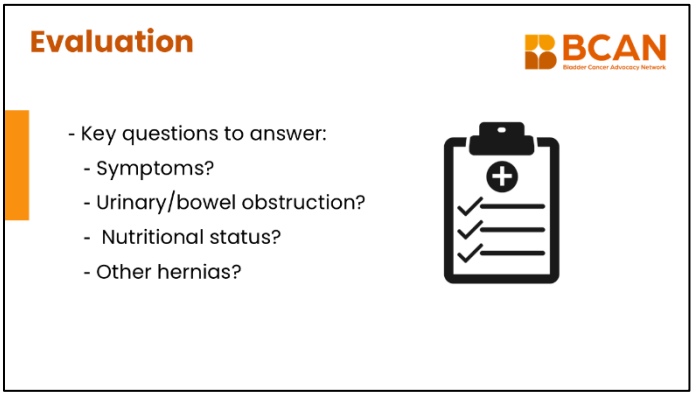
And so why does this matter? Why is this an issue and why should we care? Well, parastomal hernia, it can lead to pain. So a lot of patients that I see will say, "Oh, you know what? I have this pain that's the constant. It's always right around the stoma site." That could mean maybe a piece of intestine is stuck in there, a piece of fat stuck in there, and it can't get out, and part of

the oxygenation is compromised, so your patient's going to have pain. Also, a big issue is stoma bag application. So sometimes patients with parastomal hernias, what can happen is that it's hard to place the bag on the actual stoma and have it stick because you have this protrusion or this hernia that's impairing that ability of your stoma bag to stay on.

We also talked about bowel incarceration. That's again, when the bowel gets stuck there and it twists on itself and it loses blood supply. And what happens is the bowel actually dies. And that's an absolute emergency that should be addressed as soon as possible. It can also cause blockages in your intestinal segments or blockages in your urinary segments, this obviously warrants immediate medical attention.

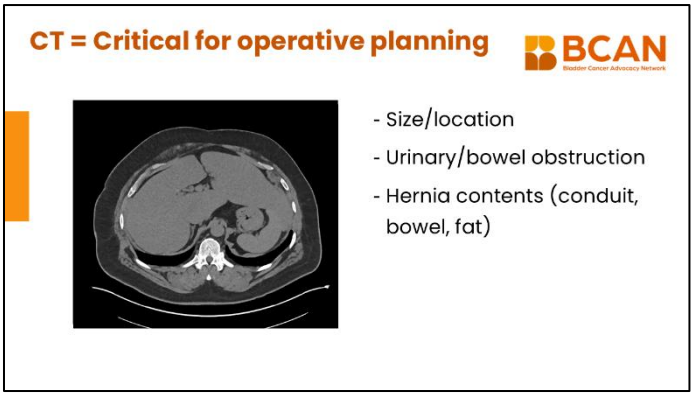
Also, another major issue is that it can decrease cosmesis. So patients sometimes will come to me and say, "Hey, I really don't like the appearance of this. I get self-conscious, when I'm going swimming or I'm at the beach." Actually a good portion of my patients who've had ileal conduit, I actually have a fair number of those who do triathlon. And I think cosmesis is an important ... If it's important for the patient, it's important for me. And so I think it's really important to see how these things can affect patients. And up to 45% may require surgery for parastomal hernias due to some kind of complication. So this is something that we should all be aware of and all should be on the lookout for.

Dr. Ziho Lee:



So when I evaluate patients with parastomal hernias, I ask myself, what do we need to evaluate and when is this a real problem? Number one is symptoms, right? Does the patient actually have symptoms? If the patient has no symptoms and it's not really that big of a deal, we don't really always jump to, "Oh, you have to get some kind of treatment." Is there any obstruction? That's a big thing. Like I talked about, if you have blockages in your urinary system where you can't empty your urine adequately or you're having problems with your intestinal segments, that becomes something where we need to jump in quickly and treat. I also look at the nutritional status, make sure patients are healthy enough to undergo some type of surgery. Then also, do the patients have any other hernias? Because if I go in and operate, it makes more sense. Why not fix every hernia while I'm in there? And so these are important questions that I always try to answer when I evaluate patients with parastomal hernias.

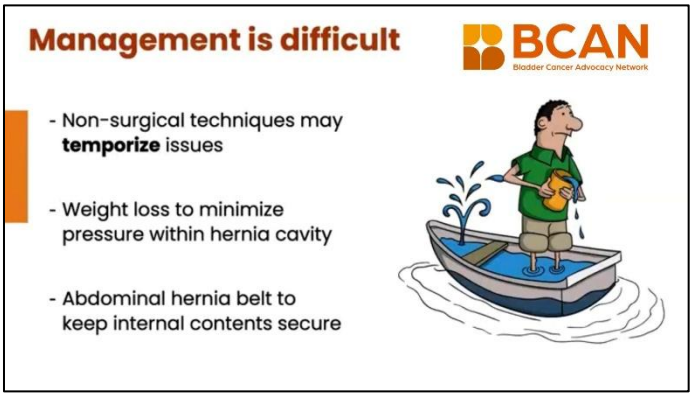
Dr. Ziho Lee:



So a CT scan, very important for operative planning. I like to show this image because when I talk to my patients, when I see patients in person, I like to show them their CT scan. Obviously not everyone is going to have medical expertise to read it, but it really puts into context what you're looking at. So if we see here, so this is a patient, this is a cross-sectional image. So we're going cross-sectionally and this is the spine back here and the top of the screen is the belly. And I'm going to pause it here as we go down and you're going to see where this hernia is.

Sorry, I missed the pause there, but we can see right here, so this is the defect in the abdominal wall. And what we're seeing is there's a very big defect and there's a piece of bowel that goes through. There's a ... I'm sorry. What you can see is it's a big space and you can see and conceivably imagine a piece of fat or a piece of intestine going through that area. Even without medical expertise, you can see, "Well, this doesn't look right." If you look on the right side of the image, this is a normal abdominal wall without a hernia, but you see here on the left side, you see how there's contents going right up to the level of the skin. And so you can see how this could be a problem.

Dr. Ziho Lee:

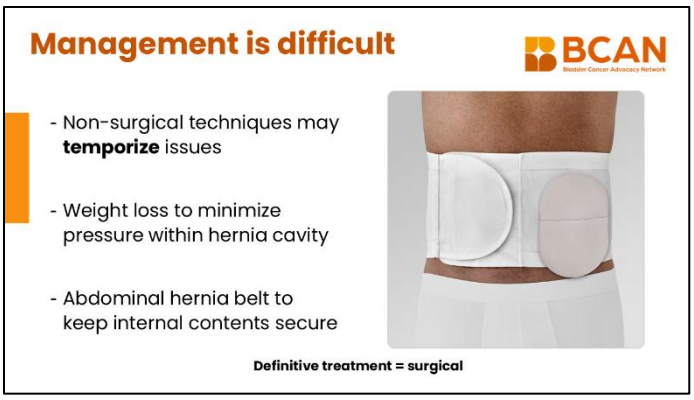


And so just to be completely honest with everyone, I think one of the most important things, at least in my practice, I do a lot of very complex reconstructive surgeries where we get referred patients from all over the country for management of complex issue that maybe not everyone wants to reconstruct. But to be honest, and I think the most important thing is just being honest with patients and being very blunt about what the expectations are.

And so to be honest, management of these hernias are very, very difficult. And one of the reasons for that is because non-surgical techniques, non-surgical techniques, you're really just temporizing the issue. And the reason is because you have this hole within your abdomen where you're having your intestines, your urinary structures, fat, just herniating through. And so because it's a structural issue, doing something non-surgical, you're really just temporizing the issue. And so I compare it to if you're on a boat and there's a small hole in your boat and all you have is a little bucket and you're trying to dump all the water out as it's filling. And so

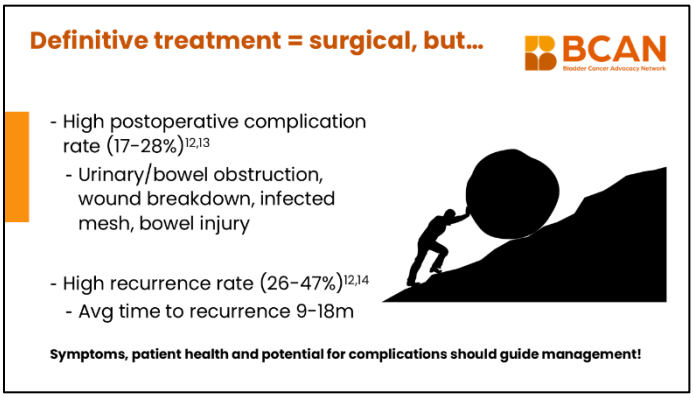
you can stay afloat with these non-surgical issues, but you're not really fixing the hole or the problem. Weight loss can minimize the pressure within the abdominal cavity, so weight loss always helps.

Dr. Ziho Lee:



And then the other option is to wear a hernia belt. And essentially what it is it's a belt that maybe some patients wore during surgery or after surgery or maybe you do now, but what it's doing is to help keeping all the contents compact and within an enclosed space. But again, as soon as you take that abdominal hernia belt off, you maybe have a cough or you laugh, you're going to increase pressure in your belly and you're going to increase the risk for that hernia to happen again. And so really non-surgical techniques really just temporize the issue. And so definitive management is usually surgical.

Dr. Ziho Lee:



Surgery is hard. Not a lot of people like to do these surgeries. Most of these surgeries, to be honest with you, are done by plastic surgeons. In my training, I never actually trained to do the parastomal hernias, but I learned with some plastic surgeons. When I got to Northwestern, I was very fortunate to work with plastic surgeons who helped me learn how to do these surgeries. And I'll go into that in a little more detail, but these have a high postoperative complication rate, so 17 to 28%. That's a high rate for me. Things that can happen, you can have obstructions. Sometimes when you tighten up that hole, you can make it too tight. You can have wound complications. A lot of these treatments require mesh, and so the mesh can become infected, and you can injure surrounding structures, namely bowel. And so this can be associated with a pretty high complication rate.

What's more important though is a lot of these issues, unfortunately, there's a high recurrence rate. In the literature, up to 50% of these can come back. The average time recurrence is nine to 18 months. Why is there a high recurrence rate? I think part of that is because naturally the fascia that we have, it's a reflection of your body's ability to heal. It's a reflection of your overall nutritional status, and so your fascia is innate to your body. And so while these surgical mesh,

you can certainly get the tissue back together, sometimes the healing process can take longer. And so in the literature, it's reported up to almost 50%, which is very high.