

THE LACNETS PODCAST

With Lindy Gardner, BSN, RN
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Transcription:

Lisa Yen

Welcome to The LACNETS Podcast. I'm your host, Lisa Yen. I'm the LACNETS Director of Programs and Outreach as well as a caregiver and advocate for my husband who is living with NET. In each podcast episode, we talk to a NET expert who answers your top 10 questions. This podcast is for educational purposes only and does not constitute medical advice. Please discuss your questions and concerns with your physician. Welcome everyone! Our special guest today is Linda Gardner, otherwise known as Lindy. Originally from Northern England, Linda earned both a Bachelor's and Master's of Science in Nursing from Dundee University in Scotland. She's an experienced clinical nuclear medicine nurse at UCLA who oversees the administration and research of PRRT, which is peptide receptor radionuclide therapy. Skilled in research, Lindy was the lead nurse for the PRRT EAP, or expanded access program, which is now the FDA approved commercial program. And also the recent PSMA directed endoradiotherapy of castration resistant prostate cancer, or PERCIST clinical phase two trial for prostate cancer. We're really excited to have you here with us today, Lindy. As some people know, Lindy and I are good friends, because we have not only worked together and collaborated at things such as the Healing NET Summit and different projects, but also because she has been the treating nurse for my husband for several PRRT treatments. So it's really great to have you. And it's really great to hear from you today.

Lindy Gardner

Thank you so much, Lisa. It's great to be with you.

Lisa Yen

So Lindy, before we get started, it'd be great to hear what got you into this field of NET?

Lindy Gardner

That's a really great question too. And the answer is very, very easy. When the expanded access program came to North America, it was pushed by a physician that worked over here to get this treatment onboard for patients of neuroendocrine tumors. And I was recruited. I worked with nuclear medicine on some peripheral things and I was recruited over to help them treat these patients in this population. And it really has expanded from there. My main background is in interventional radiology, which I was in that field for 19 to 20 years. So it's been a good transition over to nuclear medicine.

Lisa Yen

We're so glad to have you in this field. So glad you got recruited. And now you're such an ally and advocate and champion with all your work and research and therapy. So thank you for all your hard work.

Lindy Gardner

Thank you.

Lisa Yen

Well, why don't we jump right in with the first question, if that's okay?

Lindy Gardner

Yeah, absolutely.

Lisa Yen

Today we're discussing, of course, PRRT, your field. And specifically a lot of the questions that, as you know, patients or caregivers, people who are living with NET and people who are coming to have PRRT treatment, they have frequently asked you either before their therapy, during their therapy, after their therapy. So these are the kind of questions that often are directed to you, Lindy, or other nurses who are in this field. The very first question that is very common is, what might I expect on the day of PRRT infusion? So for example, what is the day like and what side effects might I experience?

Lindy Gardner

So this is a really great question. And I know there's a lot of information out there on what kind of day you're going to have, what you're going to expect. There's going to be a lot of people that experience different days. And I'd like to give sort of an overall of what the day should encompass. But depending on which institution you do go to, there may be some little differences along the way as to how that is when you go into treatment. The day is like, the best way I can explain it, it's like an infusion day if you've had previous chemo, it's very similar to that kind of a day, but not the same medication, but how that day would progress. You will be scheduled for it and you'll arrive in the clinic. And you may drive yourself or somebody drive with you because you don't know how you're going to feel out of the treatments. So on your first treatment, it's always good to have somebody come with you, just in case you don't feel like you want to drive home. When you arrive, in whichever department you're receiving the therapy, you'll be there approximately between, I'd say, four and six hours. I give that variation because again of the treating institution. Normally within five hours you should be out of treatment. When you go for the day, you can have breakfast or have a light breakfast. We don't know how you're going to feel during the therapy either. We don't know whether you're going to feel a bit sick, a little nauseous, and that can tend to happen if you've had some chemo previously, and you have felt a little sick. So we can anticipate if you had some chemo and you felt a little bit sick, then you may feel a little bit sick with this treatment. But obviously we'll give you a pre-medication to deal with that. Again, the therapy rooms may be different when you come in. There'll be a lounge chair or a gurney maybe. If you're in a different institution being treated, you may be laying on a gurney or you'll be sitting in a recliner chair. And you'll be with a nurse that will be giving the treatment on that day. Now we do start an IV. We give the medication through a peripheral IV, or if you do have a port, we can use a central line port, if that's been previously placed for you. And then it's basically an infusion, we give you medication for nausea. We will give you some hydration. It's not hydration, actually, it's an amino acid bag, which is something that helps protect your kidneys while we're giving you the PRRT. And that

infusion course for that amino acid bag is four hours. We have to run that over four hours to protect the kidneys while we infuse the PRRT. A lot of people think that, oh, it's a long infusion, it's going to be a long day. The day is that long because of that amino acid bag that we give you, the kidney protectant. The actual infusion of the Lutathera, as it's called, it takes between 30 to maybe 45 minutes to infuse that, again, depending on the institution where you are receiving the medication. So it's not a long process to actually deliver the medication that you need for your tumor. It's an actual amino acid bag that takes a longer time to infuse. And we want you to relax while you're receiving that also. So you can eat and drink before you arrive. But if you want to just hold off on eating, drinking beforehand, just to see how you feel, because there's going to be four infusions, that's going to be eight weeks apart. I believe my counterpart is going to explain all this maybe in another podcast, Dr. Martin Auerbach. But you will have four infusions eight weeks apart. So your first infusion is going to sort of set up your expectations for the next three infusions you receive after that. So if you feel comfortable when arrive, you don't have any issues, then on the next infusion you can save yourself, you can eat a hearty breakfast, or you can bring some food with you if you'd like to do that if the institution allows that. So the infusion takes roughly between four and a half hours to six hours. And your expectations as a patient is that you'll be sitting down receiving the infusion. You should feel fine during the infusion. However, I do have to say that when we do administer the Lutathera itself, some patients can have a very slight hormone response. If you have a functional or non functional tumor, you'll sense this. You can maybe send some medication going in. Very, very few patients do experience that. But if that happens, we can assist you and age you with some cooling measures. We can slow the infusion down so you don't feel that rush the same. So we have lots of little things in our toolbox to aid with that. But we really want to make it a pleasurable experience for you. If anything, you may get a little bored because of the four hours if you don't have any reading material or an iPad or something to look at. Or if you don't have any interesting people to speak to in the room. We like to keep it so it's just part of the infusion. We want to keep you up to date on what's going on and answer any questions while you're there. And this is where that nurse-patient relationship comes in. We like to start then explaining and having you understand the concepts of radiation, and all those good things, and it's your time to really ask the questions or just want to know everything that you haven't retained or you need. We are available at that point, the nursing staff in that room while you're receiving your therapy, to be basically your aid to assist in that process. Once the therapy is over, the amino acids finish obviously, we'll remove the IV and then you'll be discharged home with discharge information and paperwork. And I know we're going to enter a lot of these questions as we progress. So but that's sort of the day as it goes. It's like an infusion day, IV hydration medication with the IV, and then you go home. But as comfortable as possible.

Lisa Yen

That's really helpful and reassuring, Lindy, to hear all these things to expect and what not to expect. And just kind of to follow up and to clarify on what side effects should I or could I expect? I think this question comes up a lot. Should I expect to be nauseous? Should I expect to feel bad in any way?

Lindy Gardner

So again, this is another great question. And also, it's like an umbrella. There are a lot of different things people can feel. And I can give you some of the side effects that I've seen, in my experience administering this therapy, which are more of the common ones. But again, this isn't black and white as to how this is. As I said, we don't know whether you're going to feel nauseous from the therapy. Some people do feel a little nauseous as we're administering therapy, which is good to know, because we can tailor the pre-meds on your first administration. And we can give you a little bit more in anticipation. So

this first visit really sets you up for the next several visits that you do come in to receive the therapy. The side effects after this, the biggest one, obviously, that's in the prescribing information, and it's everywhere, is nausea. Nausea is the biggest side effect from this. We do give a small script of Zofran to help with that, if needed. A lot of patients are already on this medication, so they have it freely available. And obviously vomiting, but we really want you to take the medication so you don't vomit and to try and tide that over. Some other side effects that I have seen is flu like symptoms, maybe 24 hours later where people feel tired. Maybe they have some achy joints, and they feel like they may be coming down with something, or they just feel the medicine working inside. And it makes them feel a little tired. And this is a great segue into how long you can feel tired for. This is a really difficult question to answer because we have some patients that will feel tired after 24 hours, or it could be after 72 hours, and it may last three days. And then sometimes it can last even longer, maybe seven to ten days. And sometimes that can be the same with the nausea feeling, too. It's going to be very important to discuss with your oncologist and the nuclear medicine attending how you think you're going to feel, how you felt with chemo so we can have this pre-conversation so we can try and prepare for it. You may feel nothing. A lot of patients don't feel anything. They don't feel sick, which is wonderful. And just because you don't feel anything, it doesn't mean to say it's not working either. We just have a lot of different feelings across the board. But the nausea and the vomiting is the first main one. It normally lasts 24 or 48 hours; it can last longer. And also the general malaise, coming down with some achy joints and tiredness. They're the main things that do come across. But as I said, a lot of patients don't feel anything either.

Lisa Yen

Thank you, Lindy. Like you said, it's not black and white. And just because you don't feel anything, doesn't mean it's not working. Really good point. So the next question, and I know you've already touched on some of this already, what do I need to do to prepare for PRRT? And can I eat or drink normally on the day of the treatment? So just whatever you want to answer in this question.

Lindy Gardner

So the main thing, we don't have what they call NPO restrictions, which means we don't tell you not to eat or drink beforehand. Just whatever would be easier for you to come in, if you want to do a light breakfast if you're unsure if you may think you might feel sick, because you know your body well. And if you've had previous treatments, and you tend to feel nauseous, then a lot of patients do want to maybe only drink some liquids, or maybe want to do a light breakfast, just to see how they feel, so then when they come in the next time they can go ahead and eat. Some people just say well, I don't want to get sick with anything, so they just have a good old breakfast and come on in. We'd really like you to have a good night's sleep, which I know is extremely difficult, because you're already nervous and anxious because it's your first treatment. But you've got this, it's not that it's easy, but it's an infusion. I can't stress enough to a lot of people that I really want them to relax because I don't know what a lot of people perceive about what they're coming into. And I really just want people to understand it. It's just an infusion process. That's exactly what it's like. If you've been through chemo infusions, that's very similar to what it is. But because it's unknown, it's PRRT, a lot of people haven't had it, and there's a lot of stories out there, Lisa, about how people have been really, really sick, and they vomited a lot because of, to clarify, when we were doing the expanded access program, when this medication first came out, we used an amino acid compound to protect the kidney that was a very convoluted mix of a lot of different amino acids. We only needed two of those amino acids in the bags that we would administer to patients so we had to give a lot of volume to get in the two that we needed. Luckily now there is a special commercial bag available with exactly what we need in that bag. But a lot of the

reports and findings were from this nausea was from the actual amino acid we used back in 2017 and 2016. And in 2018, where it was this very mixed bag that did make the patients sick, and it wasn't the actual treatment, it was the amino acid that they were receiving. So when you do go out there and Google or you maybe ask people how they felt when they received it back in 2016-17, or the beginning of 2018, and they said that they were really really sick, a lot of this is put down to that amino acid bag that we gave as a kidney protection. So there's still a lot of this information around there that people really feel that when I say oh, you're not going to feel too sick, and they've read all of this information out there saying, oh, well, that's not what we saw, that's not what I read. I spoke to somebody that had it in 2017 and they felt so bad. A lot of that is put down to that compliment medication, the amino acid infusion that were meant to protect the kidney. So I really want to clarify that and it's something that's really important. And I don't want to oversimplify the fact and say oh no, you won't feel sick. The difference between the two bags has been night and day how people feel. So that's really important to understand also.

Lisa Yen

Thanks for clarifying that. And you're right. So many people had it way back in the early days, as you said, with EAP. I could see that no pun was intended when you say mixed bag. And it's amazing how much things have changed in just four to six years, how it continues to evolve and how things continue to get better. Thanks for clarifying that. So you've already touched on some of this, but this is a very common question, what are the side effects after PRRT? And how are they managed?

Lindy Gardner

So once you're enrolled, or you're receiving your PRRT therapy, we're obviously going to monitor your blood cell counts. We want to make sure that your blood work is okay after you receive treatment, and before you receive the next treatment. Obviously, we want to take the care and effort to make sure everything's functioning properly. And that your counts are ready to receive that. So we have values where you have to fall into to make sure that everything's okay. That your red counts and your white count are good. Kidney functions is good also. We don't expect any of those blood counts to change very much with therapy. But there is a possibility. And also, where you start off in your therapy. If your counts are pretty marginal before you start therapy, then we're not going to expect those counts. When I say counts, I'm talking about white blood cell counts and red blood cell counts, and platelets. We're not going to expect those counts to get better. If you're starting off very low. So we're going to really monitor you closely to make sure that we're giving you the infusions, when your body's ready to receive them. If your counts start off high, if you've got a great hemoglobin and a great white cell count and your platelets are all normal, we shouldn't really expect to see any variation in that because you've got what we call good marrow production. So your body's making all the essential elements that is used to make while you're in treatment. So that can be a common side effect. But it depends where you start off in your physical standing. This is if you say your where your blood is, as your markers at the beginning. And that will be monitored. Other effects afterwards, I feel like I need to mention this because I get this question from a lot of women about hair loss. They lost hair. And we do get some women that have some hair loss, more so more women than men. But it's not the same as what it was when we were in the expanded access when we were using the large amounts of amino acid with a lot more amino acid we didn't need. We saw a lot more hair loss in that aspect. I've seen less and less of it as we've gone along using the commercial bags. But I do have some people that say they are losing hair. I don't know why that happens. Some people do and some people don't. It's not a permanent loss. It's a noticeable loss that when they say they brush their hair, it feels like more is coming out. But there's no balding or anything like that. I'd say it's sort of considerable thinning, but it's not every patient. There's something

some feedback that we've had on that. Obviously, the nausea and vomiting will be managed by antiemetics and anti nausea medications. And there's a lot of different things that you can receive from your oncologist that would help with that. As long as you relay between either the nurse who's treating you or the nuclear medicine physician and your oncologist, they can assist and gauge with how we need to sort of tailor that medication for that.

Lisa Yen

That's really helpful. Thanks for going into the details about that as hair loss has also come up and of course nausea. So the next question is, how concerned should I be about the radiation I'm receiving, and the long term effects of the radiation?

Lindy Gardner

This is a really popular and hot question. There's been many studies done on radiation and cumulative radiation. And what that means is it's a build up over time. And anytime you have a CT or an x-ray or if you have a y-90 or external beam radiation, all of those things, that's a buildup of radiation over time. And we're all exposed to radiation on a daily basis too. So with any accumulation of radiation, if you're receiving high doses of radiation, there's always a risk. We can never say there's zero risk. There is a risk that over time that there's certain diseases that you can attribute to radiation accumulation, which are a lot of the immature blood cells in the bone marrow not fully maturing, which would lead to leukemia, acute leukemia, all of those things. But I don't want to focus on the concern of that area, because it takes a lot of radiation to actually lead up to that. And the percentage of people that have received that amount of radiation. I think there was the Erasmus Safety Data study that was done, where they looked at all the creation given over a certain period of time, and the percentages were very low at what was accumulated. I think there's something like 1% of acute leukemia when they looked at 1,214 patients in that study, and it was an international study that they looked at that would come through with acute leukemia after receiving certain high grade radiation treatments. So it is low, but it is there. But it's not to focus on that. A lot of it is risk versus benefit versus risk also, which is a question that you should have with your oncologist if this is something that's really pertinent to you. If you really need to sit down and discuss that. And also, the nuclear medicine physicians are absolutely fantastic at really explaining this if this is something that you really want to go into detail with. So there's never a zero risk, there is always a low risk there. But these treatments of PRRT, you can receive multiple treatments. Currently in the US, you can receive four treatments of PRRT for neuroendocrine tumor. And then if you have what's called progression free survival for greater than 12 months then you can be eligible to receive another two treatments. And we're hopefully building upon that. Currently, we don't have any further treatments, which would be eight or nine after the initial six. This is something that we're looking into. But if we go out to Europe, right now, there's a lot of patients that have received multiple treatments, maybe 10 or 11 treatments, and they're still functioning very happy with no other acute blood changes or acute leukemia with multiple treatments. So you really have to look at things within the realm of what we're treating, and how other people have been treated in different countries and what the build up is on that. So it's really important that discussions can be had with your nuclear medicine physician, as I said, go into that.

Lisa Yen

It's so interesting. So you're saying that the most treatments a patient has received, that you've treated at UCLA, is eight treatments? So, four, and then two, and then two.

Lindy Gardner

That was part of the EAP and then outside the EAP. So that would be correct. That was an outlying patient. But right now we are doing multiple rounds on patients that are receiving their treatments six and seven after the initial four because they've done very well on it. They've had progression free survival until they started to progress again. And then they've had a second two treatments. And they're doing very well.

Lisa Yen

Okay, so they received the initial four and then they got number five and six, and you were doing several of those.

Lindy Gardner

Yes.

Lisa Yen

And you have had at least one person that's had seven and eight, right?

Lindy Gardner

Correct.

Lisa Yen

You and I know, since that was my husband. Everyone knows that Lindy and I know each other because he had five and six, and then seven and eight at UCLA.

Lindy Gardner

Just to go back to that, Lisa. It's not covered by insurance. Currently, the extra treatments which is seven and eight. So seven and eight wouldn't be covered by insurance, but how it fell for your husband, obviously it was different. But it is currently covered for four and then as I say, if there is the progression free, and if the data falls towards after they've been scanned and the progressing after that period of time, then they can qualify for an extra two doses, which is which is pretty good.

Lisa Yen

And you've been successful getting those covered by insurance?

Lindy Gardner

Yes, we have. Which is fantastic!

Lisa Yen

And as you mentioned, people have received double digits. So more than 10 or more in Europe, correct?

Lindy Gardner

Yeah.

Lisa Yen

So it's not a thing of safety. It's more about insurance and coverage.

Lindy Gardner

Yes.

Lisa Yen

That's helpful to know. This kind of goes into the next question. What precautions should be taken, especially with small children or pets, or others in the house that might be immunocompromised. As you know, this is all in the realm of radiation safety, and how am I exposing other people.

Lindy Gardner

This is really important. And, again, what I'd like to stress here is that every institution is going to have its own discharge instructions and information for the patients that they treat. Also, if you go online you're going to see a lot of different caveats to those instructions that are pointed out there. So when we talk about the instructions and how to be safe around people, I want to say this isn't going to be black and white, it's going to be gray. I don't want you to say, oh, well, Lindy said that it has to be two days and this other institutions that it was three days or four days. Just to give a little info from the bag, the Nuclear Regulatory Committee does state that we have to give guidelines per institution. They don't give us a black and white instruction to say that you have to be discharged with this. Do this, do this do this. Like you flush the toilet twice, three times four times. It's per institution. So it's how we want to guide our patients within what is within our institution, within the department. So with that said, we look at the best way to give this information over to people is that when we look at the medication that we give, when we come up with days of not to be next to somebody for two days, or to be away from three days, or four days, it's kind of good if we break it down and take a step back and look at how is it eliminated from the body. Where do we get this one day, two day, or three day? So when you receive your dose of PRRT, 44% of it is actually flushed out through the kidneys in the first, I think, three to four hours. So before you leave the hospital, you'll have urinated in the toilet, and you'll have passed out 44% of it. So the rest of the circulating volume that's attaching to the receptors on the cancer, it's going to be going around, and then when you go to the toilet after four hours within the next 24 hours, it's going to be at 58%. I think in two days, 67% of the drug is already going to be system. I want to say drug activity. So that's why a lot of the guidelines for how far to be away from people, we say for two days. Because by the time it's passed through the urine, we've got rid of over 60% of it. So that's really good. But there's still obviously some of the radioactivity on board because it's attached to cancer. It's going where it needs to go and it's doing what it needs to do. So the instructions that UCLA give out, we do a two to three day, minimum of two, but we'd like you to do three, where we're going to stress hand hygiene, going to the toilet, for men and for women. Using paper towels to wipe so there's no urine sitting on the skin. Hand hygiene after that. And a daily shower to wash the areas where there could be some urine on the skin, as well. So just be really extra cautious on the hygiene aspect. Because we want that all to be washed away off the hands. We don't want any alcohol cleaning on the hands. If you've gone to the toilet and used paper and wiped yourself, there could be some residual urine in your hand. We don't want you to use the alcohol because you're just actually cleaning what's on your hand but not removing the activity. So you need to soap and water. Rub, rub, rub, soap and water to wash it off. I kind of digressed from the initial question, sorry about that. So, precautions around children or pets. So we have a lot of questions about pets. Can my pet sit on my lap after I've had the treatment? We say yes. If your pet makes you feel good, and your pet makes you feel better, are you going to cause any damage to your pet? While your pet will receive some small amounts of radiation, is your pet going to get cancer or anything from this? Not within its lifespan, no. The pet is going to be fine. You're not going to damage your pet. If you just don't feel comfortable with that then just don't have your pet on your lap for two days and then put your pet on your lap for two days. It's really up to you, but you're

not going to cause your pet any damage. But within the lifespan of the pet is anything going to change? Probably not. Small children? I'll go into pregnant women and small children. I'm uber cautious. I'm a mom. I had two children while I worked in this department and I was around radiation and radioactivity. "ALARA" is the main thing that everybody works towards within this area, which means "as low as reasonably achievable." It's our gold standard and that follows through with time, distance and shielding. They're the two main criterias we follow within nuclear medicine and it's self explanatory when you think about it. As low as reasonably achievable, because we can't say zero, we're exposed to radiation all the time everywhere. When we're around the source, you want to be as low as reasonably achievable for patients and for staff members and family members. And also with the time, distance, and shielding, the best way I can describe this, if you imagine a fire, you've got a hot fire, and you warm your hands over the fire. If you stand directly over the fire, it's going to be hot on your hands. If you take a step back and hold your hand, it's going to be warm. If you take a second step back, you're going to be cool. So when we talk about hot, it's kind of in that term, but with no temperature. It's just to give you that understanding of that, that's what it is. Obviously, the patient is going to be the source of the radioactivity that that's going to be decaying and 44%, as I said, is going to be passed out in the urine in the first five hours. So you can be in the same room as a child. I just wouldn't have the child sit on your lap for any period of time. You can have them in the room, they can come over, say good night to you, then go to bed. And people say what age of a child would I do that with? Well, I go up to teenagers, but the teenager is an adult. They're not going to absorb the dose, they're a lot bigger, the cells are slowly stopped turning over. Whereas if it's a baby or a pregnant woman, we don't know what the ramifications are because we haven't been able to do tests on children or pregnant women around this. So we just want to say no stay away. Because if there's no need to be close to them, don't do it. So we'll say a distance for pregnant women and children between five and seven days. With regular adults, it's two to three days. If anybody's immunocompromised in the house, that's a different part of the question. I mean, we're not going to be bringing anything in that they can catch. The radiation isn't going to change their immune response or status. There was a lot of patients were asking, can they receive their vaccinations during this time as well? And yes they can. Of course they can receive vaccinations and this treatment isn't going to put them into an immunocompromised state, unless they're already in that area where their immune system is sort of borderline. And then that's when we'd monitor during therapy.

Lisa Yen

I'm so glad you brought up pregnancy as this is a really important question that also comes up. Does PRRT affect fertility? And are there issues then with pregnancy or breastfeeding after getting PRRT?

Lindy Gardner

That's a really great question. After you've had PRRT, and you've finished the treatment, after six months, post your final treatment of PRRT which will be the fourth treatment, you can go ahead and try and get pregnant. And you can also actually breastfeed a little earlier than that. I think in the prescribing literature information, you can start breastfeeding after two and a half months after the final therapy. But no, you can go ahead and plan on having a family after six months after the last treatment. And I think with males, you should use contraceptive and birth control up to four months after the final treatment. And then also they can plan on having a family after that, too.

Lisa Yen

Thank you for addressing that. As you know, people of all ages are getting PRRT.

Lindy Gardner

Yeah, absolutely. A lot of younger patients bring in this further forward in the toolbox as well. It's really nice to see this. Especially because this therapy is tolerated so well. It's such a nice therapy to move further in the toolbox and the results can be really good.

Lisa Yen

And as you administer it to younger people, this is a common question that will come up.

Lindy Gardner

It is, yes.

Lisa Yen

Thank you for addressing that. So back to that concern of radiation safety and exposing other people. Another common question, and this is part of your discharge instructions, how should I travel home if I've received the PRRT? Do I need to sit in the backseat of the car?

Lindy Gardner

That's a really great question. And the answer is, if that makes you feel comfortable. You can sit in the backseat of the car, or you can sit in the front seat of the car. I'm going to go back originally to the "ALARA," as low as reasonably achievable instructions, and also what makes you comfortable. I am going to mention as well, which I don't think I mentioned the beginning, was when you are discharged from the facility we actually do a one meter read to see how much radiation you are giving off after you've received PRRT therapy. Now, just to give you some numbers, the Nuclear Regulatory Commission state that if you read at seven milligrams an hour and below, you can be discharged from the facility. So just take that number in mind, seven. Now UCLA has a rule to say if you read less than five milligrams an hour then you can be done charged home. I can't remember exactly how many therapies we've done. We've done several 100 therapies, and we do a read after each therapy. And with all those reads, we've done at one meter on every patient that we've treated, we've never had a patient with PRRT for neuroendocrine tumor read greater than 2.5 milligrams an hour. So we're less than over half of what the NRC recommend. And also, lower than what UCLA recommend. Most of our patients maybe read between 1 and maybe 1.7. The radiation that's been given off you as a patient is very very low. So you can sit beside whoever is driving, that is fine, or if you just want to be uber cautious, you're not going to cause any harm, but you may sit catty corner in the back, as well. Again, going back to that as low as reasonably achievable. And also your comfort, as well for you and your loved ones. As I say, each institution, this is fluid. The discharge instructions are fluid, but just having an understanding so you can make your own educated decision on where you sit in the car.

Lisa Yen

And that's really interesting that you mentioned how low people are measuring before they leave. So just to give some context, Lindy, what does that mean, 1 to 1.7, or 2.5, as you said, was the highest, what does that mean in context with other things?

Lindy Gardner

Well, that's a really good question. I'm trying to think of what an x-ray would be or something,

Lisa Yen

What does it mean? What does it mean, that it's 1 to 1.7, or 2?

Lindy Gardner

So it's like the radiation that you're getting off. We'll hold a dose meter up, and the dose meter will pick up the activity of radiation coming off. It's not like a Geiger counter, it's actually a dose meter that takes on that read, and it'll give us a numerical reading of the radiation that's coming off from that on a meter read. A physicist would be better to be able to explain it. But I know that where our cutoff points are to where we can discharge somebody home. If we had somebody that was in the facility, that say, if there were over five, I had never seen that happening, but if it did, then what we would do, we would keep them in overnight, until we saw what the reading was the next day, because there's a bio breakdown of the radiation therapy and there is also a decay process of the actual medication that's administered. So it's always going to be decaying down. The biodistribution is going to go down. It's going to come out in the urine, and also the drug itself is going to decay. So if there was a rating greater than five, you would be admitted until the next morning, which would maybe be 10 or 12 hours, and then you would have dropped down below that. If we brought each patient back into read them daily, you'd see exactly how much that number dropped down. Does that make sense?

Lisa Yen

Yeah, that does help. And again, along those lines, and I'm sure you get this question, too, people not only ride in their car to come see you or another institution for PRRT, but they also get on a plane. So how soon after PRRT can one travel on a plane, in particular?

Lindy Gardner

This is a great question. And a great person who can answer this and wrote a couple of papers on it would be Josh Mailman. And I believe most of your people listening on this today know Josh. He did a paper about the travel concerns after treatment with Lu-177. And this was something I didn't realize when we first started the EAP. So I went back to 2016, when we started administering this. Before it was FDA approved, it was not on the border controls radar that the Lutetium 177 was a medication that was being used. So there was a lot of people traveling at the time that was stopped and held up because they didn't know what radioactivity was on this person until now it's within the border control. I think the U.S. Customs and Border Protection Control would have this listed now so if you do set off an alarm, a very, very, very delicate alarm that are at their airlines, they know exactly what medication is on board with you. Depending on which institution you go to, you'll receive a flight letter and a dosing card so you can carry that with you. The dosing card will be in your wallet and it will be replaced at each therapy that you have. You'll get rid of the old dosing and you can receive the new dosing card, and it'll actually have the medication name on there, and the time and the date it was dosed, and the amount you were dosed. And you'll carry that with you. Also if the institution gives you a flight letter, or any kind of after visit summary which would be the discharge instructions, all the paperwork could be there. So it's always good to carry that with you if you are going to travel. Now how soon can you travel after PRRT? We have patients flying in on the morning. Well, we did. Not so much more now because it's more commercially available so patients can be treated closer to their homes. But originally, we had patients flying in in the morning and then going home in the evening. But I don't want to say that there should be no issue. If you're traveling internationally, just make sure that you do give yourself a little extra time going through because you could be stopped, it could take a little longer. I want to say that it is improving some of the feedback that some patients are given, some are stopped, some aren't. Josh would be a great resource to ask them this, because I know he reaches out to a lot of patients that do travel and have a lot more experience on this. But always make sure you got your paperwork and your dose card, and go a little earlier. But if you're traveling three or four days afterwards, your dose

measurement will be extremely low. But equipment that they use at the airline facilities, it's very, very sensitive equipment. So it can still pick up traces of that. So just to keep that in mind.

Lisa Yen

That's helpful to know. And some people might even want to know how long should you carry around that dose card?

Lindy Gardner

Until your next treatment. You do not get rid of that dose card until you're treated again, and then you'll get a new one. And then after you finished your final treatment, you're going to carry that dose card for minimum two months until after your last dose. The new equipment is very sensitive, and it could still pick up microscopic amounts that are still in the body.

Lisa Yen

Thank you for that and that specific information, too. So again, along with these discharge instructions, people also wonder, do I need to sleep in a separate bed? And if so, how long?

Lindy Gardner

That's another really great question. And there's going to be a lot of schools of thought on this. And again, I say this is fluid. We have some patients that don't have a separate room, and they don't have anywhere they can sleep away from the loved ones. So there is no limitation to say that you can't sleep in the same bed. If you sleep one on one side, one on the other, we recommend that you don't spoon or cuddle or any close contacts the first two to three days. We prefer you just to make sure you stay on your sides. Again, if you want to use the "ALARA" concept, as low as reasonably achievable, and you have an extra room, sleeping in the extra room for a couple of days, and then you can jump back into your bed that you were regularly sleeping in before. And also that goes with toilets and bathrooms. People ask can I use the same toilet as my partner? And yes you can as long as there's no spills of urine on the seat. Make sure that men it's better if you can sit down instead of splashing when you stand up to urinate. If you can sit down and urinate, that's great, so there's no splashing of urine. Do you flush the toilet once, or do you flush the toilet twice? Flush the toilet twice the first couple of days. Is there going to be any harm or damage if you don't flush the toilet twice, and you forget to flush the toilet twice? No, there isn't. This is just, again, to try and keep things as low as reasonably achievable. Just to make sure that we're trying to cover all bases. So if you do forget to do something, or you jump into bed with your wife and you cuddle her all night because you forgot. Are you going to damage her? No, you're not. We just like to keep things as low as reasonably achievable. And I just want to stress that I don't want people to get really worried or really anxious that they're going to really hurt somebody because they're radioactive when they're around somebody. Oh my God, I stood talking to that pregnant woman in her first trimester for five minutes and I didn't know she was pregnant. Are you going to do any damage? No. There's not going to be any damage done in that period of time and I don't want you to put that weight on your shoulders that you did something wrong. Because you didn't. The right way to describe it is just to be conscious, to have a consciousness about it. But you're not going to hurt anybody or damage anybody.

Lisa Yen

Thank you. That's that's really reassuring, explaining why there's a variance of information out there. There's a certain guideline and principle, as you're saying. And there's a comfort to it, knowing that it's not so black and white. Thanks for that. And our last question is especially coming up right now in age

of COVID. Am I immunocompromised after my PRRT treatment? So I know you've already touched a little bit on this, but there's questions about being able to get vaccines. Do I need to avoid getting vaccines or boosters? Am I more susceptible to bacteria and viruses after PRRT?

Lindy Gardner

This is a great question. And I'm going to go right back to the beginning when I answered the question about when we were monitoring blood counts. These are great questions to ask the medical oncologist as well. If you're white counts and neutrophil counts, and all those counts that they look at on the blood, if everything's within the normal realm, you're fine. You're not going to be open to any extra bacterial or viral infections because your blood work is in the range to fight off all these things. If you're compromised on the borderline, then yes, there could be a little susceptibility there. But it just depends where those blood counts are. And we're not going to give you or administer you this infusion therapy if you're borderline. We may just extend it an extra four to six weeks before the second treatment so we can get your counts where they need to be. So the main thing is, would you be more susceptible? If you were already on borderline in the beginning, then yes, we could increase that susceptibility. If all your counts, meaning your white counts are normal in the beginning and they didn't drop, then no, you wouldn't be more susceptible because your body is already at the level where it needs to be. So you have to look at it in that way. Yes, we want you to get your vaccines. We don't want you to put off the vaccines because of the treatments. That is never an issue.

Lisa Yen

Thank you. That's really helpful. And we covered a lot of information here. I'm just wondering, Lindy, what would you say the big takeaways are that you want to leave the listeners?

Lindy Gardner

I think the big takeaway is that we've been doing this now for a couple of years since the FDA approved it in 2018. And there is a vast amount of information out there. And this is very fluid. As you said, things are getting better, the amino acid has got a lot more tolerable. We're treating people younger so more questions about fertility and pregnancy. So it's very fluid. I want the experience to be a good experience. I don't want people to feel anxious or worry, because they've already got enough to deal with with the disease process that they're going through. I want them to understand that they're not going to hurt anybody around them or the loved ones or people that look after them. They won't hurt anybody. There's also questions that we talked about, people are incontinent with the urine. As long as you dispose of the urine, you wash your hands, please use gloves, if you know you're going to be incontinent and shower daily. There's ways to work around this. You're not going to hurt the people around you. Again, we just want to give you the tools to make sure that you feel comfortable with your treatment and what to do after the treatment. And feel free to Google and reach out and look about, but you got to be careful with the information that you get because you don't know whether it's old information or bad information. And also the information will vary. It's not the same at each institution. It does vary a lot. But if you can go away with some of the main guidelines, if you hit it in the middle, that's probably where the truth is going to lie.

Lisa Yen

Thanks for that, that's really helpful. Things are fluid, ever-changing, fluid between institutions, changing as they're evolving, and whether institutions are getting more experiences, more research, you're learning more, or perhaps there's going to be future developments, as well.

Lindy Gardner

You never know.

Lisa Yen

And as you're saying, it's not black and white. Even though people are zebras, it's not black and white in terms of what exactly they need to do.

Lindy Gardner

Each experience for everybody is going to be a little different. You just have to keep that in mind. But I do believe after you've had your first treatment, and then you've lost that anxiety, it'll feel a lot better for you. But everybody's not the same. Some people do have a good experience. Some people, not so good. But we work with that, and we work as a team to try and make it the best experience for you.

Lisa Yen

And thank you for doing that and for all your hard work, your dedication working, not just at the bedside and with the teamwork that you do at UCLA, but also in the greater NET community and in the greater research community. Thank you for all you do. It's so helpful and without you we wouldn't be as far as we are and continuing to push forward.

Lindy Gardner

Thank you so much, Lisa. I appreciate that. This is just very close to my heart.

Lisa Yen

Thanks again for joining us today. Lindy. We really enjoyed having you. And we look forward to hearing more about PRRT next month with Dr. Auerbach. Thanks for listening to The LACNETS Podcast. We want to thank our presenting sponsors Ipsen Pharmaceutical and Advanced Accelerator Applications. For more information about neuroendocrine cancer, go to www.LACNETS.org.