EPISODE 46: Spotlight on Advanced Practice Professionals (NPs and PAs) with Tiffany Valone, PA

Lisa Yen 00:00

Welcome to the Neuroendocrine Cancer Foundation podcast. I'm your host Lisa Yen. I'm the Director of Programs & Outreach, as well as a caregiver and advocate for my husband who is living with neuroendocrine cancer. In each podcast episode, we talk to an 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.

Lisa Yen 00:30

Welcome to the Neuroendocrine Cancer Foundation Podcast. I'm really pleased to introduce our guest for today, Tiffany Valone. Tiffany is a certified Physician Assistant in the Department of Gastrointestinal Oncology, and she started her career at Moffitt Cancer Center in Tampa, Florida, in gastrointestinal medical oncology in 2006. She was promoted to Supervisor of Advanced Practice Professionals in 2014 and was awarded the Advanced Practice professional of the year in 2015.
And she was also awarded with the North American Neuroendocrine Tumor Society's AHP/APP of the Year in 2024, a great honor and achievement.

Tiffany is a Florida native who completed her Bachelor's Degree in Occupational Therapy from the University of Florida in Gainesville and her graduate degree in Physician Assistant Studies from Philadelphia University in Philadelphia, Pennsylvania. She is board certified by the National Commission on Certification of Physician Assistants and licensed by the State of Florida Board of Medicine. Tiffany is

a co-investigator on multiple clinical trials and plays an active role in the training and mentoring of new gastrointestinal oncology advanced practice professionals, physician assistant students and pre-physician assistant students. She thoroughly enjoys educating others and has presented at state and national conferences on the topics including colorectal cancer, pancreatic cancer and neuroendocrine tumors. We've had the opportunity to get to know each other through several neuroendocrine cancer conferences and are thrilled to have her join us on the Neuroendocrine Cancer Foundation podcast.

As we know, neuroendocrine cancer care involves a multidisciplinary team, and sometimes it can be confusing who's playing which role in each team. So, in today's episode, we will highlight the role of an advanced practice professional in neuroendocrine cancer care. And one fun fact about Tiffany is that she enjoys traveling with her family and three kids. In fact, she just returned from skiing and visiting national parks in Utah. Welcome Tiffany, it's wonderful to have you here with us today.

Tiffany Valone 02:33
Thank you so much, Lisa. It's an honor and privilege to be here with you today.

Lisa Yen 02:37
So Tiffany, if you don't mind, we'll just get right into it, because a lot of what we want to talk about is kind of addressing the questions and I know you've had a long history, as we just heard from your introduction, many years in this field, and specifically in GI cancers and in neuroendocrine, which may be uncommon or common for others in this field. So, you've really been a leader in this field, and we're really thrilled to have you with us.

Tiffany Valone 03:02
Thank you.

Lisa Yen 03:03
So, the first question is really foundational. What is a nurse practitioner, physician assistant, or, in general, an advanced practice professional?

Tiffany Valone 03:11
So, I know there's all different titles out there. Advanced Practice Associate, Advanced Practice Professional. Physician Extender is another title that you may have heard. But really within that group, I think you can lump physician assistants, nurse practitioners. You may have heard of nurse anesthetists, which help with anesthesia in the OR as well as anesthesia associates or AA's. So, four of those groups fall into the group of advanced practice provider [APPs] or physician extenders.

Lisa Yen 03:41

Yeah, I think what's confusing about the term, especially for you as a physician assistant, some people think that you're an assistant to physician. Is that how you would describe yourself as physician assistant, or assistant to the physician?

Tiffany Valone 03:55
Well, what I say to patients or those unfamiliar with our discipline is that we have an abbreviated, I would say much abbreviated version of medical school. Generally speaking, they are master's degree programs. So, we've completed a bachelor's degree, but in various disciplines. My undergrad is in occupational therapy, but I had other students that were in my class that may have graduated with biology or sports medicine. So, we come from varying backgrounds, but we have to take a graduate level admissions test and then get into a physician assistant program. The physician assistant program is generally around two years, and the first year is all didactic classwork. So, they're really condensing that four years of medical school into one. So, we don't go nearly in depth that physicians do into their studies, but we really get a high-level overview of physiology, anatomy, and then learning the various sections that we need to know of medicine. And then the second year of PA school is spent in clinicals. And depending upon your program and where you're at in the US, some focus on primary care or rural medicine, but there's mandatory ones like emergency medicine and so forth. But majority of programs just barely touch on oncology. So, I maybe heard just carcinoid syndrome and knowing just flushing and diarrhea, but that was it. If anything, we focus more on the more common cancers, and maybe that was just one day topic, and that was it. So, most people that go into oncology either have a personal interest in it afterwards, and most of our training is really on-the-job training.

Lisa Yen 05:36
On-the-job training. That's probably similar to physicians, where they also get a paragraph or maybe an hour of neuroendocrine. So, I guess it can be confusing for patients. They might be expecting to see a doctor and they see you. Would you say you're a doctor, or are you a doctor? How are you different or similar?

Tiffany Valone 05:55
By no means am I a doctor. So, I tell that to patients when they're first meeting me, that I am their physician assistant. And at Moffitt, how we do things is all new patients will see the medical provider first. And at Moffitt, we have two medical oncologists that specialize in neuroendocrine tumors. And then there is about three APP's, because I do now only, unfortunately, two days a week in the clinic because of all the managerial aspects of my job. So, we have three APP's that are focused in neuroendocrine tumors. And so, a patient will come in and first see the doctor, and I will be very honest and say there's no really rhyme or reason. It could be with our scheduling department that the patient may get put with me the next time, because that's when the patient is available or there's availability on our template. And so there are patients that I have had on my template for 10 years that

don't request to go back to see Dr Strosberg. Now, he is still their attending physician, but we have developed a rapport and a relationship together that they fully trust me and know that if it is time for Dr Strosberg to come in and see them, that we will make that happen, and they just feel more comfortable following in my care. There's others that like to go back and forth and may see me one year and then Dr Strosberg the next year. So I know it kind of varies at different institutions of how that plays out. It's funny because I still run into what I call "new patients," and so they'll think that I just joined Moffitt, and I've been coming here 10 years, and I've never met you, and so I'm still meeting some of Dr Strosberg's patients who have been here with our practice for a long time, which is always a pleasure to do.

Lisa Yen 07:33
Okay, so to be clear, you're not a physician, and you have a lot of similar training, and you also use this word “provider.” So, what does it mean to be a provider?

Tiffany Valone 07:44
So, I tell patients, I am there to help them through their cancer journey. So we can, along with the physician, evaluate the patient's laboratory results. We can evaluate the patient's radiology results, and along with the physician, develop a treatment plan, manage the patient's toxicities or side effects to treatment. I would say that is one of the things that APP's are really known to do well. I am very happy to say that I get to spend more time generally than the physicians do as a whole, with patients, because they are pressed to see more patients than we do. So, I do like the fact that I have a dedicated 30-minute time slot for my patients, and if I need to go over, we go over. So, I can help those patients in that regard. You know, the time when I'm escalating up or saying, "Okay, this is out of my wheelhouse. I don't feel comfortable." That's when I'm getting the physician involved. So, if I'm not really sure what direction to go with the patient, then I will be asking my attending at that time. "Okay, this is what I'm thinking, but I'm not sure what would you like to do?" And then the doctor would either come into the room or maybe follow up with a phone call to the patient and say, "Listen, I did discuss your case with the attending, and this is what they're recommending, and then move forward from there."

Lisa Yen 09:06
Sounds like a lot of teamwork.

Tiffany Valone 09:07
It is a lot of teamwork, I think, a lot of having a lot of trust in each other. I mean, that took time. Dr Strosberg and I have been working together now for 16 years, so I'm sure at the beginning that was not the case. I was probably going to him after every single patient and asking his advice. He was a

wonderful mentor, because, like I said, going in and starting at Moffitt in 2006, I had nearly no oncology experience. So, he was a wonderful and instrumental mentor into learning neuroendocrine.

Lisa Yen 09:39
It's wonderful to have a champion and a mentor like that. You know, we touched on nurse practitioners. And as you know, I'm a nurse practitioner, but how was your role similar to or different from nurse practitioners? Because some people might see a nurse practitioner at a different institution, and then at Moffitt, there's physician assistants. So what's the difference?

Tiffany Valone 09:55
I think the difference really varies per state, and I'm just going to speak from Florida and Moffitt Cancer Center, because I think it even differs at your institution and in the community. And as a whole, at Moffitt, there is really no difference. We are all held at the same in terms of hiring, what our pay is, what our expectations and our roles and responsibilities. If you look at the breakdown, there's actually more nurse practitioners at Moffitt than PAs. So I think Florida is a pretty nurse practitioner friendly state, but when it comes down to it, our training is a little bit different. Physician Assistants are trained in the same model as doctors on the medical model, and nurse practitioners, to my understanding, are trained in the continuation of the nursing model. Some of the differences that you may encounter per state is nurse practitioners can prescribe narcotics. Physician assistants only short term and need to have the physician signing off. Sometimes, nurse practitioners can actually run their own clinic. So that wouldn't be seen at Moffitt, but outside in the community. Whereas PAs are always working in conjunction with a physician or multiple physicians. So I would say those are the overall differences. You may see more PAs in the OR first-assisting, but at Moffitt as an umbrella, we are really viewed and utilized in the same fashion.

Lisa Yen 11:14
So, from a practical aspect, for a lot of patients, they probably see them in a very similar role across institutions.

Tiffany Valone 11:22
Yes.

Lisa Yen 11:23
So you've been at Moffitt since, wow, a long time. As you said, you've been there since 2006 and you've been alongside Dr Strosberg for all that time. I'm curious, how did you enter the neuroendocrine cancer world?

Tiffany Valone 11:34

So, it was actually by chance. When I started in 2006 I was working with two other physicians at Moffitt in GI and that was where, in my early days, I did concentrate on colorectal and pancreatic cancers. And both of those doctors, at some point in time, had moved on from Moffitt, and it was around three years into my career at Moffitt that Dr Strosberg was finishing his fellowship with Dr Larry Coles and starting to grow his neuroendocrine practice. And so, I was asked if I would join him and help grow his practice. And so here we are, I think, 16 years later, and so very proud to say that I work alongside Dr Strosberg and Dr Haider. She has joined our practice in the recent years, and we have our neuroendocrine surgeons and nuclear medicine team, and so we really do have Center of Excellence for neuroendocrine tumors.

Lisa Yen 12:31
Yeah, you have a strong team there at Moffitt.

So, you mentioned there wasn't very much training in neuroendocrine in your schooling. So how did you learn about neuroendocrine cancer?

Tiffany Valone 12:41
So besides Dr Strosberg's mentorship over the years, I started going to NANETS, which is our annual symposium, very early on, and I tried to attend the meeting every year. And I would say a lot of the information and knowledge that I gained is through that Symposium. Also the Healing NET, which is another foundation that I was invited to for several years. I would say, getting together with all of the national, international thought leaders and just listening. So I'm just trying to absorb everything from all of the experts over the years. So those are probably the two main avenues of gaining knowledge. And then, of course, my self-study at home, we have Up-to-Date, publications. You know, as we know, Dr Strosberg is very well published, so I try to keep up with all of his studies and read the latest data. And then we have Taymeyah, who's great, into research, so I have her to ask any of my research related questions, and what's new down the pipeline. So I think using my team. The neuroendocrine community is amazing. I always tell my colleagues that there's a conference that you need to go to. It's such a close group of providers. I will admit I was pretty intimidated when I was very young in my first couple of years, but now it's just a warm, welcoming group, and we learn so much from each other. So, it's something I look forward to every year.

Lisa Yen 14:01
It really is an amazing community, and your team at Moffitt is very prolific. So I can only imagine that staying up to date with the studies, the publications coming from Dr Strosberg and Taymeyah alone is enough to keep you up to date.

So, you mentioned NET experts. Could you be considered a NET expert?

Tiffany Valone 14:19
I would think in the regard of an APP NET expert, I guess I could put myself finely into that bucket. I mean, I do thoroughly enjoy mentoring new colleagues and at these conferences, getting to see the new advanced practice providers that are coming into the NET community, and kind of guiding them with my experience with the organization, and my experience, just as a whole, of working in neuroendocrine now for 16 years. So, I guess, with time. I guess I could say that.

Lisa Yen 14:49
I mean, you've been there for so long, and certainly very knowledgeable about the disease and the management.

Tiffany Valone 14:55
It's been fun to watch the growth. And coming just from when I started working, it was really just somatostatin analogs, and that was it. So getting to see all of the RADIANT studies come through over the years, then lutathera, and now Cabozantinib. So it's a very exciting field, I think, probably one of the most exciting fields, with all of the research being done and new treatments. So, it's very exciting.

Lisa Yen 15:17
I love that you're excited about it. We need that in the field. It's very contagious.

So, I know you've touched a little bit about your role in Moffitt and with the team, but if we could just expand a little bit more on that. What's your role within the neuroendocrine cancer world, and what does it look like with your medical team?

Tiffany Valone 15:32
I'll just say, like our whole team, just to expand upon it, because it really takes a village and a multidisciplinary team to manage our neuroendocrine patients. Within that whole team, I think what a patient can expect, and not all patients will see all of these members of the team, but probably the majority of the members of the team during their journey, and that would include possibly meeting with a surgeon that specialized in neuroendocrine tumors, our medical oncologist, APPs like myself, and then we have supporting nurses on our team, and so they're really helping us on the back end. So like, let's just say, for an example, I'm prescribing a drug to a patient, and they need to be enrolled in a patient assistance program or prior authorization, so my nurse is helping me. So that way I can continue moving on and seeing my next patient and keeping on task, helping me do all that on the back end. So, I will be remiss if I don't say the importance of our supporting staff, which is our RNs and then we have certified medical assistants [CMA] that help collect records. I would say most of our patients at Moffitt are coming from two plus hours away. Many coming from out of state, and so it's a

lot of care coordination with getting prior records. And then if they have community oncologists where they're receiving their monthly somatostatin analogs, making sure that communication is there. So our CMA staff is very helpful with that.

And then we have our nuclear medicine team, so they may not be introduced right away, but at some point, if our patients are eligible for radioligand therapy, then they are meeting with the nuclear medicine team as well. Then in the background, you have your pathologist, who are re-reviewing the patient's initial pathology to be sure that we agree with whatever outside pathology they're coming in with if we didn't do the initial biopsy. And we sometimes utilize our radiation oncologist if patients need to have radiation. So when we say a multidisciplinary team, it really is multiple facets. And then that's not including social work, dietitian. We have our own GI dietician dedicated to our GI patients at Moffitt, and a lot of the time is spent with neuroendocrine patients. So that's what the whole team looks like.

Lisa Yen 17:48
It really does take a village, and as you said, so much care coordination and with all the people involved, sometimes patients can feel a little lost. So, let's start from the beginning. If I'm someone with neuroendocrine and I come to the institution, how does it determine which provider I even see?

Tiffany Valone 18:03
So, we actually have a what's called a scheduling zing tree that is based on the patient's pathology, and then if the patient's been self-referred versus referred from an outside physician. And so those who have higher grade tumors we want to see within two to three weeks, and those that can wait may be scheduled farther out. And then they could have a preference of which provider they want to see. Some that are directly self-referred, you know, say, referral to Dr Haider. Then we try to go with what that direct referral has been. So that's how patients get into Moffitt. And then after that, like I said, whether they see Dr Haider or they see Dr Strosberg, they may continue two additional appointments with them, and then all of a sudden get transferred. I don't mean transferred like their whole care is being transferred, but a year later they may see me and then see me for a while, go back to Dr Strosberg, et cetera.

Lisa Yen 18:59
Just to clarify, people can request to see a certain provider?

Tiffany Valone 19:03
They can, absolutely. They may wait longer. The instance just happened this week that the patient was referred and got scheduled out next month, and we saw the pathology and it was high grade, and we said, "No, we need to see this patient sooner," but that would result in them seeing a different

provider. But we then get on the phone with the patient and explain the importance of seeing them sooner than having just their requested physician. Usually, 9 times out of 10 the patient is okay with that once they understand the urgency of needing to see them sooner.

Lisa Yen 19:34
And if someone doesn't know who the net experts are and doesn't know the names and they call up your institution, for example, would they automatically get assigned to one of those two providers?

Tiffany Valone 19:34
Yes, at Moffitt only just speaking from our institution, we only see patients who have biopsy-proven diagnosis for neuroendocrine cancer. So, unfortunately, you can't even get in the door unless you have that biopsy. So once you have that biopsy of neuroendocrine, if you don't know who to see, that's when the scheduling has that zing tree that says, “Okay, if they're low grade, they can go here. If they're high grade, they need to be scheduled within two weeks.” If we can't make that happen, then they escalate up to the team and say, “Listen, we have this patient, but there's no availability. What can we do?” And that's when the team is working on overbooks and so forth to get the patient seen.

Lisa Yen 20:22
Oh, that's helpful to know that the requirement is a biopsy-proven neuroendocrine cancer. So someone with the paperwork, the pathology report, that shows neuroendocrine cancer of some sort.

Tiffany Valone 20:32
Now there are patients, the other way to get in is if there is no diagnosis but say there is a small bowel or a mesenteric mass with liver metastasis, then they could be routed to our surgical team. And our surgical team would perform the biopsy, get it ordered, and once they have the confirmation of neuroendocrine then they would refer to the medical oncology team, or surgery would see them if it was a surgical issue first. So that's the other way to get in if you don't have a biopsy right away, is to start with the surgical team to get a biopsy.

Lisa Yen 21:06
That's really helpful to know, because this is, as you know, common. People don't yet have a diagnosis, but they think they might have neuroendocrine cancer.

Tiffany Valone 21:13
Yes.

Lisa Yen 21:14
And what patients would you see? Or another APP?

Tiffany Valone 21:18
So, we basically would see any follow up patient. Doesn't matter of their grading, like we don't just see the patients that are doing exceptionally well and are on just SSA's. We see a variety of patients, from patients who have had their tumors resected and are just being watched on surveillance, to very sick patients that are on active treatment needing to be seen every couple of weeks. I think the biggest thing for patients to know is that their attending physician is always in the background. I assure my patients that all the time. The way that Dr Strosberg and I work things out, if it's not an emergent situation for the patient who I'm currently with in the clinic, then I will put in my note what my plan is and what my concerns are, or I don't know next steps. And he is meticulous about reading my notes on his non-clinic days. And then he gets back to me, and he says, "I agree with this." Or "No, I think this is the avenue we need to go. Please let the patient know. Please order it." So then I'm calling the patient back and letting them know, “Your case was reviewed with Dr Strosberg. This is exactly what he thinks, or he agrees with me, and we're gonna go along with my plan,” and then that way they know that I'm not making the call. It is Dr Strosberg, who is their attending physician leading their treatment.

Tiffany Valone 22:35
That's a really helpful explanation, and that was actually gonna be my next question about what this team approach is like, and when you would see a doctor, I think there's sometimes some anxiety about if I see a nurse practitioner or a PA, does that mean that there's not a doctor involved? And I think you explained that, your open communication with him and how that works pretty clearly.

Tiffany Valone 22:53
And if there is an urgent situation that needs addressed at that moment while I'm with the patient, we're either in clinic together, or if he's at another facility, or I can reach out via cell phone or email. He's very responsive. The physician is always involved. And if I get a scan that I'm not sure of the findings on the CT, and we're ordering a PET scan, then I'll put the patient with Dr Strosberg the following time so that if they have any outstanding questions, they can ask him at that point.

Lisa Yen 23:23
And that was going to be my next question, who goes over scans and labs, those kind of things? Is that something that you can do?

Tiffany Valone 23:29
Yes. So any of the providers, and what I mean by provider is the advanced practice professional, whether it be the nurse practitioner or the physician assistant, or the doctors, can go over the scans, and so we can bring the scans up on the computers and show the patients a side-by-side comparison of what we're looking at. We do hope in most instances that the scans have already been read by our

radiologist, but that's definitely not 100% of the time. In those instances where we don't have a final impression from the radiologist, I am giving my own interpretation to the patient, saying I've done the side-by-side. I think things are stable, but I will call you later on, once I see that final so that you know indeed, that we've checked the boxes and everything is good, that I didn't miss anything. And there are times that I do miss subtle things that may not even be related to their cancer or may be and that we have to do additional things. But I think for the most part, the patients are very appreciative of the follow up that happens afterwards, just so that they can be assured again that the radiologist did review it.

Lisa Yen 24:38
Yeah, you're sure to dot the i's and cross the t's. And speaking of the scans, who's the one who orders the scans and then also the treatments? Is that something you can do?

Tiffany Valone 24:48
Yes, we do all the ordering along with the physician. So basically, if I'm seeing a patient in clinic, then I'm placing the orders for their next follow up visit, and that can arrange anything from stat studies that need to be done, like, for instance, if I expect possibly a pulmonary embolus, or if I expect a blood clot, I may be ordering a Doppler just for that day. Or if they have new pain that they're telling me about, I'm ordering a stat CT scan for that day. So yes, we have privileges as an advanced practice provider to order anything that is necessary to take care of the patient. And then there's in between appointments that patients may be messaging us through our triage system. That's another duty that I have throughout the day, checking those messages, getting back to the patients, and then putting in those additional orders that may need to be addressed. So, it can be medications, ordering medications. I do have to send all narcotics and controlled substances, including lomotil, which is a very common drug use for carcinoid syndrome diarrhea, to propose to Dr. Strosberg to sign off. But that turnaround, usually the patients don't even see that. It's pretty seamless.

Lisa Yen 25:54
Okay, that's really helpful. And we talked about all the different people in the multidisciplinary team and the whole village that can be involved. So, if I'm the patient or caregiver and I have a question or a concern, who do I communicate with? And what's the best way to communicate?

Tiffany Valone 26:08
At Moffitt, we have a patient portal, which I think most institutions are going towards these days, we really encourage patients to enroll in their patient portal. It is electronic, so we understand that some patients are not comfortable with using the computer or smartphones. I know even for myself, as technology evolves, I have to rely on my younger counterparts to help me out. I can't keep up. But the two ways would be via electronically through the portal, they would email a message. It shows them

who their providers are. So drop down menu, and they can select my name. They can select Dr Strosberg. Generally, though, then that goes into a triage group that our nurse manages, and then the APP is usually the first person to see all of those messages. And so, I would be trying to help all of those patients' messages, the ones that I need Dr Strosberg's opinion on. Maybe I didn't see them last, and I don't know if I can clear them from our surgery that they need, then I am escalating them up to Dr Strosberg to get his advice on.

So, the other way, besides electronically, is we have a phone number that the patient can then call. So I make sure that all of our patients have the phone number. Sometimes I actually enter it in the patient's phone for them, so that they can know where to find it. And that number is acting the same as the portal. So, we have specialists that answer the phone, 24/7 and they basically type out the message the same way to the team. So they would say, “This is what I have going on, or I need a refill with this. I need this message to go to Tiffany Valone in GI,” and then they would get the message to me.

Lisa Yen 27:45
If someone is seeing you and Dr Strosberg or Dr Haider, do they direct messages to you or Dr Strosberg or Dr Haider?

Tiffany Valone 27:52
It doesn't matter. We're all as a team, so it's going to go to the team. What happens is our neuroendocrine nurses look to see who saw the patient last. And then, since I work usually with Dr Strosberg, if it's a Strosberg patient or myself, I would get those messages. If it's Dr Haider, her APP would get those messages so it would be caught by the neuroendocrine team.

Lisa Yen 28:16
Okay, that's helpful to know it's, again, teamwork. A lot of patients come in from out of state, so how is then, the follow up information communicated to their local oncologists?

Tiffany Valone 28:25
That's a great question, and that sometimes can be a challenge, because of trying to get in touch with offices and the physicians. We love when referring physicians give us their cell phone numbers, and we're happy to give our cell phone numbers out to the physicians as well, because obviously that makes things easy, that we can text and just email each other if need be. But otherwise, we do sometimes have to go through the front office staff, and then we'll get the message, "He's in with seeing with patients right now. He'll need to call you back." And so that can get tricky, but we do our best, especially when there's changes with the patient's treatment plan. So, if patient is doing great and just coming to see me for restaging scans and labs and they're on treatment that is working, I'm probably not going to call their physician. I just don't have the capacity to do that every time. But

definitely when there's treatment changes, that we're recommending a new treatment. If it requires that the oncologist, local oncologist, see the patient more frequently, or the patient wants to go to their local oncologist more frequently, then that is something that we are communicating, usually by phone. And if not, if it's like the situation I said, where patients are stable and just seeing me, then we do rely on the sharing of notes. And so, I encourage patients when they come to our institution, every time they go to checkout to make sure that the physicians that they want to get our records are listed as their referring physicians in their chart. And so, then when my notes are done and signed off by the doctor, there's usually about a two-week lag, but those notes then will get sent to the corresponding referring physicians.

Lisa Yen 30:01
That's a really helpful practical tip to make sure the referring physician's name and contact information is there.

Tiffany Valone 30:07
And they can put it could be their cardiologist that they want to know, their primary care. Any amount of doctors that they would like for them to get their oncology notes is acceptable.

Lisa Yen 30:17
That's helpful, and cell phones are always welcome, so you can communicate directly with them. So, one of the challenges for neuroendocrine cancer patients is when there's what feels like disagreement or contradictory opinions, whether it's someone who's a NET expert and a local oncologist or two NET experts. What advice do you have for patients when dealing with that?

Tiffany Valone 30:37
I imagine that that can be very confusing for patients and troublesome and not knowing here you have a doctor that you've seen for years in the community, and you trust. And now you're seeing a new doctor who you've been referred to, but maybe you're getting a contradictory recommendation, but they're the expert. So what I like to highlight with patients if we're having treatment discussions is the data. I feel like data is what drives our treatment recommendations. So what the data shows us, and then also, most of the time, patients are gonna have choices. So then it is a discussion of the provider, hopefully laying out the landscape of choices going over if the patient wants the data high level or not just this is what is proven to be effective. These are what the regimen looks like, what the side effects look like. For you, based on this, we think this is the best option. But if you wanted to do this, you could and highlight why we didn't put that number one. Because you have diabetes or because you have a history of cardiac stents, maybe that's not why we're recommending this drug above that one. So, I think keeping patients informed about all of that and having them as shared decision makers is key,

because not all patients want to have really aggressive therapy, and so I think that is an important caveat for us not to be remiss about.

Lisa Yen 32:03
You name some really important things, because sometimes people feel like, how come there isn't like, one set algorithm, one set way? Shouldn't it be all standardized by now? And you're taking into consideration people's values, and there are other issues going on in their lives, whether it's medical or family or other things going on, and it's all very important to have the shared decision making and personalize their care.

Tiffany Valone 32:26
And I think that's another thing that is so exciting about the NET field, is it's not a one glove approach that fits for everybody. You know, it is very individualized based on the patient's pathology and everything we've just discussed. What their wishes are, what their comorbidities are, overall, how strong are they, and then having that shared decision together, of this is what we think would be best for you, but also, what is it that you're hoping for and wishing for and how can we get there together?

Lisa Yen 32:55
Yeah, getting there together. So, I think we'll end with this last question, how do you continue to learn and keep up to date with neuroendocrine cancer? And if someone was new to the field, or say, a patient wanted their APP or their local oncologist to learn, how would you encourage them to spread the word?

Tiffany Valone 33:14
So, I definitely think besides the avenues that I mentioned before that NANETS has their National Symposium, there's also regional meetings now. I think it's different what I would recommend for providers getting into the field, and then for patients. For patients, there's definitely our advocacy groups. Yours being one of them, and Florida has started their own within the last year. So, I think definitely getting involved there is extremely helpful. I know you've been instrumental at helping patients, connecting them with various institutes and where they need to go. So, I think getting involved there is number one for patients. And then there's various patient conferences throughout the year that patients can go to. There's these podcasts that highlight different either treatments out there or providers and what we do. So, getting that exposure of the NET field out to patients.

And then I do think it varies depending upon your patient and how high level, but there are some patients that love to read all the publications. So they do come in and they tell me, you know, I've read the latest NETTER2 data, and they want to discuss it. So I tailor it a little bit to the patient that I'm speaking with. But in general, I think those for the patients are great avenues. And then as providers,

the homework that I give new providers is Up-to-Date. There's all different segments of neuroendocrine, starting from small bowel to lung and rectal and surgery treatment approaches. So honestly, I know back in the day, I had a really, really thick pile, and just one week at a time, I would attempt to review that information. But if they have access to be involved with the organizations, I think that's a great way to get that knowledge.

Lisa Yen 34:55
And it's becoming more and more accessible, because NANETS also has the podcast. I know, INCA has the one-hour CME platform for community providers as well that's free. So, there's other free avenues for people to learn.

Tiffany Valone 35:09
Absolutely, and a lot of these conferences are now giving a virtual component. So, if you don't have the availability or accessibility to go in person, you could still get the material by joining the virtual event and sometimes just seeing the recorded sessions afterwards.

Lisa Yen 35:24
So, sometimes there are providers who are also patients. Which way would you recommend them going, whether medical conference or patient conference?

Tiffany Valone 35:32
Well, I like NANETS, where we have both. Over the past handful of years, we've had you and the wonderful organizations represent the patients, and I do think that that is honestly the best approach, because I think for the researchers and the providers and the audience, hearing from the patients and the patient's caregivers has been very instrumental in also helping us to understand the journey and what patients go through, and opening up our eyes. Maybe that it's not just about the next scans in the treatments, but how the patient symptomatically is doing, and the psychological component of the patient's well-being, and all of that that we may accidentally jump over thinking we're just focusing on the treatment. So that has been brought to the forefront of our thoughts. And so, I think that has been very helpful.

Lisa Yen 36:22
What I really appreciate is that partnership, because NANETS' mission is to educate and teach providers, and then with the patient organizations, being able to address patient needs and provide education that way. And doing them back-to-back, side-by-side, especially at regional events, is so helpful, and we can all learn together. I really appreciate that collaboration and teamwork.

Tiffany Valone 36:44

Yes, I couldn't agree more.

Lisa Yen 36:46
Well, thank you so much for your time and for all you do for the neuroendocrine cancer community. It's so incredibly special to have you in this field for so long, and we're really grateful for all you do on behalf of the NET patient community.

Tiffany Valone 36:59
I appreciate it very much, and I hope I can be here again in another 10 or 20 years, talking about it more.

Lisa Yen 37:05
We hope so too, and we look forward to that. Thank you so much.

Tiffany Valone 37:08
Thanks so much. Take care. Bye.

Lisa Yen 37:11

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