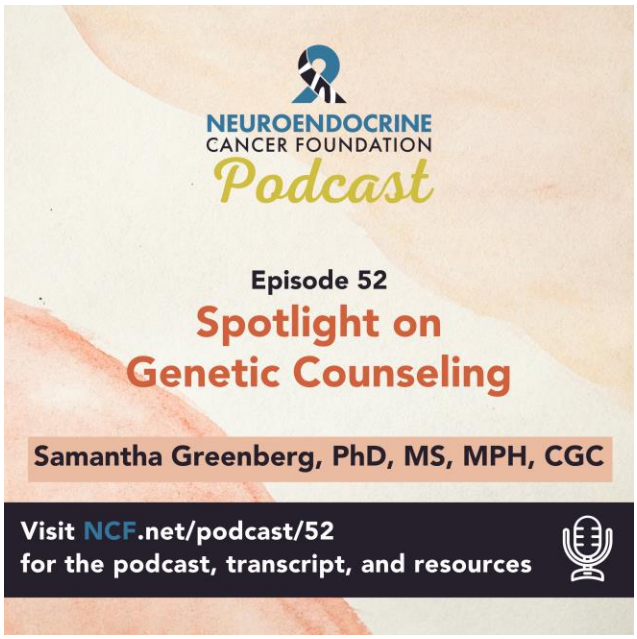

EPISODE 52: Spotlight on Genetic Counselor

Speaker: Samantha Greenberg, PhD, MS, MPH, CGC

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.

Welcome to today's episode of the Neuroendocrine Cancer Foundation podcast. What is a genetic counselor and who should see one? How do they fit in the neuroendocrine cancer care team, and what do genetic tests really mean for patients and their families? Joining us today is Dr Samantha Greenberg, Director of the UT Southwestern Genetic Counseling Program. She will help us understand the role of genetic counselors, walk us through what to expect from a consultation, and explain how genetic testing can impact care for both patients and loved ones.

Dr Samantha Greenberg is the founding Program Director of the UT Southwestern Genetic Counseling Training Program. She received her Master of Science degree in genetic counseling and public health from the University of Michigan. After teaching middle school science with Teach for America in Tulsa, Oklahoma. In May 2024, she completed her PhD at the University of Utah. As a cancer genetic counselor, Dr Greenberg has provided clinical care across a variety of indications and facilitated the development of multidisciplinary teams and genetic clinics for patients with prostate cancer, von

Hippel Lindau syndrome, and paraganglioma/pheochromocytoma. She is the co-director of the paraganglioma program at UT Southwestern which received a Center of Excellence designation from the PheoPara Alliance in September 2025. Her passion for raising awareness on the genetics of neuroendocrine tumors stems from her working with patients and a curiosity for how to optimize identification of patients with hereditary risks. I had the pleasure of first meeting Dr Greenberg at an international pheo para conference in Prague and was impressed by her passion for what she does. We also had the honor of having her as our speaker for our February 2023 webinar on the genetics of NETs. Her passion for what she does is inspiring, and I think you'll really enjoy our conversation demystifying the role of a genetic counselor. So welcome Samantha, and if you could share a fun fact about yourself?

Samantha Greenberg, PhD 02:34
Yeah, thanks. Hi, Lisa. So good to be back and just really excited to chat today. My fun fact is that amidst all of the clinical care and being someone who's always really liked to stay busy, and so ever since I started my genetic counseling career after graduation, I've always had a part time job. I started at Charming Charlie, a color-coded accessory store, and then was the Candle Queen at Bath and Body Works, selling people all the holiday scented candles. And most recently, I actually now work part time in a guest services role at AT&T Stadium, where the Dallas Cowboys and major concerts come through. And it's been a really fun experience to have a counterbalance to all the work that I do here at UT Southwestern.

Lisa Yen 03:14
That is such a fun fact. I mean, like, you don't have enough on your plate.

Samantha Greenberg, PhD 03:19
I know, you know, there's something about staying busy that I find incredibly healthy. And so after I finished the PhD and some of those other things, and we moved to Texas, I just really needed just a little bit more to fill my plate, and this was the perfect thing to kind of take advantage of all that the Metroplex has to offer.

Lisa Yen 03:36
And really, as you said, balance, right? Adding more richness in your life.

Samantha Greenberg
Yeah.

Lisa Yen 03:41

Well, what a fun fact. And would you mind also sharing with our listeners how you got in the field of neuroendocrine cancers.

Samantha Greenberg, PhD 03:48
So in my very first year of genetic counseling training, I worked part time with our cancer genetics clinic, and we had a family... Part of what we used to do when we established the family history in a visual diagram called pedigree, is that we would label the pedigree for each family member, the family number, and then the individual number. So, if the family was family 1001 the very first person we saw in that family would be 1001-01 and the second person we saw would be 1001-02. And I saw a family with a **succinate dehydrogenase mutation, an SDHB mutation**, that was at increased risk for hereditary paraganglioma and pheochromocytoma. And we saw by the time I left in my one year of working there part-time, we saw up to 46 individuals. So, their family number dash 46. And prepping those cases, while I didn't see that many of the family, really got me interested in the condition as I did my clinical rotations at Michigan. In that same clinic a year later I got to meet some people from that family, and so getting a chance to see how hereditary forms of neuroendocrine tumors affect patients at the very beginning of my career helped inspire some of that work. And then when I started my career, I was really lucky to have incredible mentors and colleagues who said, "Hey, we're interested in this project." And I said, "Oh, I was about to do the same thing." And so thus launched a research career in studying how to optimize genetic testing for neuroendocrine tumors.

Lisa Yen 05:15
We're really grateful for your interest in this area. This means a lot to us to have people like you in our corner who care about what we're going through.

Samantha Greenberg, PhD 05:24
You know, I think that a lot of people don't often think about when we work in cancer genetics, there's so many what I would call, quote unquote, more common cancers. Right? Your breast, your prostate, people that over 10% of our population are affected. And then we have our patients with neuroendocrine tumors who go through such diagnostic journeys, and they go through these stories that are quite a bit different. And so, it's important that we talk about tumors and genetic risk for everybody no matter what the tumor is, no matter what that risk is, and no matter how common it is. And in fact, for specific types of neuroendocrine tumors, we know that a higher proportion of people with those tumors have a genetic risk compared to some of our more common cancers. And so, I think finding a niche where you're in this space that we don't talk about as much, but it's so imperative that we talk about it, that the right people get to genetics has led that fire burn for coming up on a decade of research in this field.

Lisa Yen 06:20

That fire burning is evident, and we're so grateful for it. As you said, a lot of people know about common cancers, and a lot less know about neuroendocrine. So, people like you who know and understand neuroendocrine are incredibly appreciated. And not a lot of people know what genetic counselors do. And these are very common questions. We all are concerned about genetics, and is this hereditary? And what is our risk? What is our risk for our kids?

So, I guess if we could just jump into the questions and take a step backwards, look at the big picture first. And to start with, what is a genetic counselor and what kind of training is needed for this role?

Samantha Greenberg, PhD 06:58
So, genetic counselors are masters trained healthcare providers. I often equate us similar to an advanced practice provider, like a nurse practitioner or a physician assistant associate who is really focused just in genetics. And our role is really twofold. One, to help facilitate the identification and diagnosis of hereditary conditions. And two, to help with the facilitation of adapting and coping to a genetic condition. And so, the genetic and the counseling are separate and together in that way. We are working with patients who have just discovered that they have a hereditary risk for cancer and that their immediate family members could also have that risk. That is helpful, not only to make sure we're doing the right testing to identify whether they have that risk, that we're doing the right screening, that we're looking at early detection and or prevention. And at the same time acknowledging that we've essentially added another hat. I talk a lot about people have a lot of identities. You may be a sibling. You may be a parent. You are a daughter or a son, right? You are a child to somebody, right? You have a lot of hats that you wear in your life, whatever your work hats are. And so what we do, inherently, if somebody is diagnosed with genetic condition, is we add a hat to their life, and we have to think about how we help them cope with that and ensure that it's not a hat that gets worn often, that it's worn when it needs to, but it doesn't overtake all of the other things that make someone who they are.

And so, a genetic counselor typically goes through about two years of training for their master's degree, and then we have a board certification process at the end. And so, you're typically looking, if you are looking for clinical services to be seen by a certified genetic counselor, which assures you that someone has gone through that master's training and that they've passed their boards. Now genetic counselors exist in lots of specialties. Today, we'll just talk about cancer, but you may have intersected with a genetic counselor during the reproductive process, either before conception or during pregnancy. Some people see a genetic counselor for pediatric conditions, and then others see them for heart, lung, eye, brain, you name it, there are a variety of genetic conditions. And so, in this space, a cancer genetic counselor is the person who would typically be seeing patients with neuroendocrine tumors. But I just want to note that you may intersect with genetic counselors in other aspects of your life, because ultimately, we serve patients across the lifespan.

Lisa Yen 09:18
Thank you for giving us the lay of the land and really also highlighting how thoughtful genetic counselors are about adding that extra layer, that hat, the information that they're sharing. Not just relaying bad information or hard to digest information but then helping with the coping process as well.

Samantha Greenberg, PhD 09:36
One of my favorite analogies that I talk with patients about and I think is relevant, whether it's genetics of NET or otherwise, is related to...I kind of tell a story that you're standing on a bridge over a stream, and there's lots of things going over, underneath you. There are fish, there's rapids maybe. I don't know. There might be people kayaking. You never know. And let's say there's a piece of trash. And as you're standing over the bridge, you're watching all of those things go through. You're kind of observing all of them, but not any one thing necessarily sticks out. But when somebody gets to a point that now they're standing alongside the stream or whatever it is. They're no longer on the bridge. They've taken that piece of trash out of the water, and they're staring at it. Where did it come from? Where is it going? They're missing the beauty of the people and the fish and the rapids and all the other things that's happening. It's usually a sign that we are not in the right balance of where we need to be, and that we need to help people get to a place that they are standing on the bridge over the stream, enjoying everything that it has to offer and acknowledging that sometimes you're going to focus more or less on certain things. And that's kind of how we look at having a genetic condition. It shouldn't run your life. If you're staring at it like the piece of trash that you're missing all the other things, not the genetic conditions are trash, right, but just from an analogy sake, then a genetic counselor or a social worker or somebody in that space is going to be incredibly helpful to think about how we cope in it. And so, we do a lot of that preliminarily, and then if somebody needs additional processing, then that's when we move on to people who specialize more in the counseling side of things.

Lisa Yen 11:05
What a beautiful analogy, really helping people develop that awareness. I mean, needing to be aware of what's going on and yet still being able to move on with our lives and live fully.

So, I know that you've worked with multidisciplinary cancer teams. I know you did in Salt Lake City when you were there at Huntsman with Dr Heloisa Soares. What is your role in a multidisciplinary cancer care team? And how do you collaborate with other providers?

Samantha Greenberg, PhD 11:32

I'm looking at my fun fact and realizing it's quite relevant, because I'm going to make a football analogy. My learners tell me often that I love analogies, so I will pre-apologize to anybody who does not like them as much. But I have always described this as the **special teams** of a football setting. So, if you're thinking about you know, you have your quarterback. This might be the oncologist, if you're starting with a surgeon, wherever that person might be. And then you also likely have some kind of coordinator, someone who's helping guide where things need to go, and figure out where that is. And then you also have your defensive side of things, the rest of your health, the rest of your wellbeing. You're dealing with one thing. And then you've also got all the preventative things happening likely at the same time to maintain your health. And special teams is really that person that comes in and basically hands the ball between where it needs to go. So if a surgeon or an oncologist says, "Hey, we really want to go make sure you get a genetics workup," we're going to take that ball, we're going to run through the genetics workup, we're going to write up a summary of what it means, then we're going to pass that back to the care team.

And so, when we think about that, I like to think about as almost like a transitionary period. Not a lot of people, when they first come to genetic counseling, are going to spend a lot of time with us. They'll have a visit, they'll have some follow up, and unless there's a hereditary condition or something we need to do continued management of, they're likely going to go back to that primary care team. But we're going to sit on that care team at tumor boards, at case conferences, at discussions, and make sure that the team knows, one, whether genetics needs to happen and hasn't yet. Two, whether it's happened and what the outcomes are. And three, if somebody has a genetic condition, what we need to be doing.

So, one of the places we see often is, let's say somebody has had some form of treatment and we're determining next steps. Maybe they're moving into surveillance and the post surgery follow up would say, okay, every six months for however many years, and then maybe we stop. Then maybe we go every few years. Well, if someone has a hereditary condition, they might actually need that screening no less than every year. And so, it's our role to collaborate and say, you might release them from this protocol, but they need to stay in this surveillance realm. We need to stay being proactive and staying on top of things.

And so, sometimes you may never see a genetic counselor, if you don't qualify. Know that we're behind the scenes at tumor boards and case conferences. If you meet with a genetic counselor, like I said, typically it's kind of a one to two visit max, as we work alongside the care team. But again, we're behind the scenes. And then the last option, when we see something hereditary, sometimes we become the quarterback. If you do not have a risk so let's say you are a family member that doesn't have a tumor, you have relatives that have one, and we've identified a genetic condition, then the genetic counselor alongside a high-risk physician become that quarterback. Now we are not ordering

the testing. That typically is done by the physician that we're partnering with, but we're typically helping be that quarterback and making sure that we're navigating the next steps of a genetic diagnosis.

Lisa Yen 14:19
Yeah, I love that analogy of the special teams and how that relationship can change or evolve. It's fluid depending on what the situation is. So how does a genetic counselor become involved in a care of someone with neuroendocrine cancer? Do they come find you? Do they get referred? How does that happen?

Samantha Greenberg, PhD 14:38
So, most patients are referred. And so essentially, there are a set of guidelines that care teams use to identify individuals who would benefit from genetic testing. And while genetic counselors don't just order genetic testing, that's usually a good baseline, particularly because we don't want to add a bunch of visits that aren't needed. And so, what we really want to do is look at individuals who might have an increased risk for a hereditary condition, something that runs in the family, something that they were predisposed to from the start. We want to identify it so that it can potentially impact treatment decisions, impact surveillance, and then also think about what we need to do for family.

And so typically, that happens when someone has been diagnosed, or if someone has a diagnosis and something has changed. Or we've discovered there are two pathology types within the same tumor or somebody has a more aggressive diagnosis than we thought. There are a few different criteria that can then change whether somebody would benefit from genetic workup. And then the provider would typically refer the patient.

That being said, neuroendocrine tumor is a new space for where we have not always had strong guidelines outside of one very specific type of NET, paraganglioma/pheochromocytoma, for genetic testing and counseling. It's only been in the last few years that we started to say maybe we should be considering and there's guidelines to consider genetic evaluation for multifocal pancreatic neuroendocrine tumors, duodenal NETs, really thinking about gastrinomas and specific types of neuroendocrine tumors, that we're now starting to see this expansion of who requires genetic workup. And we're probably in a space where there are individuals who might have been diagnosed a decade ago that we wouldn't have necessarily recommended genetic testing, and now we might consider it.

Samantha Greenberg, PhD 16:28
I want to take a second and back us up, because I'm using some really specific terms, and I want to give people a broad sense of what we mean when we say "**consider**," and what we mean when we say "**recommend**." So, the guidelines that we typically refer to can come from a NET association. So, the

North American Neuroendocrine Tumor Society, NANETS, has a guideline on certain treatment mechanisms. We also have our **National Comprehensive Cancer Network, or NCCN**, they develop a set of guidelines, and they actually have very specific NET guidelines on what they recommend for genetic risk evaluation and genetic testing. That genetic risk evaluation can happen with a genetic counselor, or it can happen with a quarterback, whoever the primary provider is on that care team, and then genetic testing can be facilitated. But they make two really specific distinctions. The first is a recommend, and the second is a consider. And so you heard me say, we consider testing in these spaces, and you didn't hear me say that we recommend, and that's because a recommend is a stronger recommendation, for lack of a better term than consider, but both of them, there's sufficient enough data to say we should at least think about genetic testing. Where our **recommend says that "we recommend that somebody gets genetic testing"** and **consider means "we could do genetic testing we defer to the provider for some of their discretion.**"

So, in the recommend category for NETs are your pheochromocytoma, paraganglioma, individuals who might have multiple tumors in the NET space, and we might be suspicious of multiple endocrine neoplasia syndromes. So, people that might have like a foregut carcinoid in the lung, thymic or gastric area. As I mentioned, a duodenal NET, pancreatic neuroendocrine, some pituitary adenomas. You can hear all of these are endocrine-based tumors, but if somebody just has one of them, then they typically fall into that "consider" category, because we're learning more. We have yet to have really strong studies that say yes, a high proportion of people with these tumors have a genetic finding. But we move into the "recommend" once somebody has two or more of those. And so the more we think about it, when people hear this and they say, "Oh, I have multiple of these tumors. Or two people in my family had one tumor each," those are the things that start to make us think about these, quote unquote, red flags.

Samantha Greenberg, PhD 18:46
We can consider genetic testing and anybody who has any one of these tumors, specifically the pancreatic, duodenal, et cetera. But we get to a stronger place that we say, "No, we need to be doing genetic testing, we recommend it" once we move into people that either have multiple or they have a diagnosis of paraganglioma/pheochromocytoma, and the one I didn't mention was a medullary thyroid cancer. So those are the ones that we're going to start thinking about. And as we talk throughout this, some people are going to hear this and be like, why didn't somebody recommend genetic testing? And the answer is, things are a little bit fuzzy still. We've only just gotten these recommendations in the last few years to consider genetic testing in some of these populations. And so, the navigation of that takes time for us to get more data and more information and figure out what the true best practices to move something to a full recommend.

Lisa Yen 19:33

That's really helpful. I mean, the field is evolving, so what was recommended years ago is maybe different now. So just to make sure I understand this clearly, there are some conditions like paraganglioma, pheochromocytoma, medullary thyroid cancer, that is a "strong recommend." Okay, hands down, those people get genetic counseling.

Samantha Greenberg, PhD
Yes.

Lisa Yen 19:55
And then there's another bucket. So if people have two or more different types of neuroendocrine, so for example, they have pancreatic neuroendocrine and also a lung neuroendocrine, then that would be a "recommend."

Samantha Greenberg, PhD
Yeah.

Lisa Yen 20:07
Okay, but if they only have one type of neuroendocrine small bowel, that is a "consider."

Samantha Greenberg, PhD
Yeah.

Lisa Yen 20:14
Okay. And then the other kind of bucket that you alluded to, this is a common question is, if two people in the family have neuroendocrine, would you say that is a "recommend"?

Samantha Greenberg, PhD 20:25
Yes. So, this is where things get really unique in terms of, you're kind of almost looking at like a "**mix and match**." I think you bucketed the personal history really well. And then to your question, what happens when someone has a personal history plus a family history? And so, I like to, I think, to your point, I think what you described really well is there's almost two in a family get you to a "recommend." So if it's myself and a first or second degree relative, now we recommend it because two individuals with a NET in relatively close proximity, first/second degree relative, so up to grandparents, out to aunts and uncles, down through grandchildren, would be something that we think about doing genetic testing for and that we move into the "recommend" category.

Lisa Yen 21:06

And how much does age play into it? Of course, there are people who are young parents, and they're really concerned about getting diagnosed young passing it on to their young kids.

Samantha Greenberg, PhD 21:16
So, I think you hit on this really core topic of cancer genetics. Broadly, we know that the biggest risk factor for tumors or cancer is age. The older you get, the more likely someone is to have a cancer diagnosis or a NET diagnosis. Any kind of tumor. And so, when we see them at younger ages, that raises again one of those red flags. Could something be going on? Now, what's unique in some spaces is that there are some tumor types that we say, "hey, if you're at this age, then we recommend genetic testing. And if you're above this age, we consider it because we know that there are differences in the likelihood of getting these tumors based on age and genetic profile." In the neuroendocrine space, in the NET space, we don't actually do that. It's just about the presence of a tumor at any age. And so, that is unique in the sense that we, I think, would have higher suspicion if somebody was diagnosed at a younger age, but we wouldn't change our recommendations for testing based on age at diagnosis. I also think this is another place where the "consider" part and clinician discretion comes into play. If I see someone and my gut doesn't feel right, we'd rather have that person see a genetic counselor and consider genetic testing and or go through workup to complete that process. And so, one of the things that we always talk about when I talk with providers is that there's this thing we teach that's essentially a gut feel. That not every guideline, not everything can fit into one of a specific box. And so, sometimes you have to look at it and say that just doesn't feel right. And so, to your point, if someone's diagnosed at a younger age, or there's multiple relatives diagnosed at younger ages, even if they're in that "consider" bucket and we're still uncertain, it doesn't hurt to say, "Hey, I'd like to do this because my gut doesn't feel right." And that is something that we rely on our provider's discretion, and we rely on patients to have that conversation with the provider, to allow them and to make that decision together about whether or not this is something that might be beneficial for genetics.

Lisa Yen 23:20
Yeah, there's that gut feeling to trust and also that relationship and the conversation that's necessary.

Another common question and concern that comes up is, what about family members that don't have a diagnosis, but they're concerned because a relative of theirs has neuroendocrine? Do you work with those people who don't have a diagnosis of neuroendocrine?

Samantha Greenberg, PhD 23:41
Yes, so this is a little bit harder, but if somebody has a first degree relative, so parent, child, sibling, who meets some of these "recommend" criteria. So, if you have a family member with a medullary thyroid, you have a family member with a paraganglioma, you had a family with multiple NETs, that family member also meets criteria for testing. We would recommend they undergo testing.

Now I also want to be broad about this and acknowledge that we're talking a lot about guidelines, but sometimes people...Go back to the stream analogy. If this is something that is weighing on you, you have a strong family history of cancer, maybe NET, maybe NET and other cancers, we are always available as genetic counselors to talk through this process. There are some places that may triage and say, "No, doesn't meet criteria or it does," but not really. Our goal is to make sure that people know what a real risk assessment looks like. And most genetic counselors and genetic counseling clinics have more than enough capacity for us to say, "Hey, come in. Tell us about your family history. You have a gut feel. You have a family history of NET and other cancers, let's assess." And the reason why that's incredibly important is that there can be combinations of tumors that maybe aren't NET-related that we see that maybe force us to think about a broader test or a more specific differential or something in that category.

And so just like clinicians are going to do workups and tests and all those kinds of things, for us, that family history is that core tool that we're going to use to make sure that the right genetic testing is getting ordered and that we've assessed for the right conditions. And so, we're always happy to see people without a diagnosis. Typically, we recommend someone have a family history of in this case, NET. Or NET and or other cancers, or just cancer in general. And to your point, people with multiple diagnoses, early ages of onset, or what we would say, more cancer than we'd expect to see in a family, are all welcome to contact genetic counseling or consider genetic testing.

Lisa Yen 25:46
That's helpful. I know that there's a range people who know for sure someone in their family has some sort of neuroendocrine that they're well aware of, and it might have a hereditary risk. And there's some people who know that family member of their say, a parent passed away, but it was X number of years ago. They don't know the details of the neuroendocrine. And you're saying that you have an open-door policy.

Samantha Greenberg, PhD 26:07
Yeah, you know, I think we are challenged often, cancer genetic counselors as a whole, by the past. If I see an 80-year-old patient, their grandparents may have served in the war, had different exposures that led to cancer risk. In Utah, we used to have a space in the state where the wind would blow in a specific pattern from the nuclear test sites in Nevada. Many, many years ago, I had a patient once say, "Oh, we used to take field trips to the nuclear test sites in Nevada and look at that." And then everybody in the city had an increased risk due to environmental exposure, and so there was a lot of cancer in the family. I mean, those things I'm sure, we may find out in 30 years that there are things nowadays that have that same risk, but we are then in settings where we have to piece apart the environmental risk, the history, and the fact that, to your point, many, many years ago, we sometimes

open people up, said there was quote unquote cancer everywhere, and closed them up. Or that's kind of what we hear through the stories, and that doesn't allow us to have a really strong family history of "the cancer started in X place." And so there are people that will say, "I know it was cancer, but I don't know what kind" or "I know that this number of people had this exposure." And to your point, that's part of the reason for the open door, is that we know that there's some nuance and uncertainty when we think about medicine 30, 60, 90 years ago, depending on how far back your family history goes.

Lisa Yen 27:33
Thank you for that understanding. So, you were talking about testing, and we're talking, in general, about testing and these types of tests. So, there are so many terms. If you could help us break down the terms and what they mean: genetic, genomic. We hear NGS, what are these terms?

Samantha Greenberg, PhD 27:49
That's a great question, and I'm going to share some what I would call quote unquote, technical definitions. But I also want to be clear that we use a lot of these terms in a variety of different ways. And so, if you are talking with somebody and you're a patient, and you have questions about what is the difference, I would ask. Because you want to be sure that what people are talking about when they talk about genetic, genomic, NGS, all of those kinds of things, is very clear and delineated.

So, I want to take a broader step back before I define those things and talk a little bit about what I would say are the two main types of genetic or genomic testing that occurs in cancer care in general. The first is **somatic testing**. This is essentially where they are doing a genetic test on the tumor itself. Tumors and cancer in general, are just an accumulation of genetic changes over time that have not kept the cells in check, and now they are growing and dividing out of control. So, a somatic test essentially can look at the status of whatever tumor sample they're looking at in the moment and say, "these are some of the genetic changes. We could potentially target these. These are very specific to the tumor themself."

That's different than **germline testing**, which is what we primarily order as genetic counselors. Germline testing looks at your healthy cells in your body from the day you are born to look at whether you had a hereditary risk for cancer that put you at increased risk from the start, and those look at a different subset of your cells. Those can be passed on in generations, unlike your somatic testing that's very specific to that tumor itself.

And so typically, while genetic is more single-gene, hereditary-focused, **genomic is a little bit more all of our genome**, all the things related to DNA. I think oftentimes when people reference them, the genetic testing is the germline. Did I identify a hereditary risk that put me at increased risk for this tumor that I now have or that runs in my family?

Genomic testing is typically what can be done on the tumor or other aspects to identify what's happened over time.

And then the **NGS** is stands for **Next Gen Sequencing** is typically a tool that we use to facilitate genomic and genetic testing. And so, people will see NGS as a technology listed on one of those that then represents the type of technology that occurs. But I would say typically, when somebody asks about genomic testing or NGS or next gen, they're typically asking about somatic testing that was done on the tumor that we evaluated it for.

Samantha Greenberg, PhD 30:01
I want to add one more definition that you probably never hear about, but exists and is part of the difference between germline and somatic, and where all of these fit in. Your genetic code is made up of a bunch of letters. We've got 20,000 genes in our body. They define who we are, and each gene has 1000s of letters in it. And NGS is typically able to look at whether those letters are spelled correctly, or whether there's a misspelling that might have led to a mutation that again led the tumor and cells to grow and divide out of control. Or they can sometimes also identify big pieces that might be added or missing. But the ability and what they're looking at is a little bit different when I'm looking at a tumor than when I'm looking at something in the germline or something that's hereditary risk. We are going to use some additional technology that may or may not be used in the tumor side, because what we want to be sure of is that if there are small pieces of the gene or a small amount of letters that are added or missing, in this case, duplicated or deleted, we also need to be able to pick those up. And the criteria that we use in germline testing is a little bit different than what we use in somatic testing. And so you're never going to hear us talk about deletion, duplication, or MLPA, or some of these other phrases that we don't even need to go into. But I want to just highlight that one of the small differences between that genetic and genomic is that the genetic testing, the germline testing, is telling us about potentially increased risk. And so, we use it as a diagnostic test to tell us if somebody has increased risk in the future. But a genomic test or a somatic test is going to tell us what happened now in the moment for this tumor. And so, it's very thorough, it's very comprehensive. It uses a lot of the sequencing, but it's not going to be quite as nuanced into some of the small areas that we need to make sure we've checked in the germline side that may not be as important when we're looking at the tumor. And so, we hear NGS, genomic, somatic, in the same bucket. Tumor-related, genetic, more germline-related.

Lisa Yen 32:44
That was a really fantastic overview, just so I have this down. Okay? Somatic is another way to say tumor itself, genomic, these are all used similarly, and that's what's happening with the tumor itself, what's happening right now in the moment. And that's different from germline, what's happening in the DNA, what's happening that you can pass along to your kids, that has maybe risks for the future.

Samantha Greenberg, PhD 32:40
Correct.

Lisa Yen 33:10
And NGS is a tool for either.

Samantha Greenberg, PhD 33:14
Correct. NGS is typically a piece of both tests, but when we talk about NGS, we're typically thinking about it in relation to the tumor based on how we talk about it.

Lisa Yen 33:23
Okay, can there be genetic changes in the tumor?

Samantha Greenberg, PhD 33:27
That's a great question. So, because your healthy cells are what we look at in the germline testing. If there was a predisposition or some kind of genetic change that you've had in all of your healthy cells, it is possible to also see that in the tumor, a great example of this are **B-R-C-A or BRCA mutations**. These are not associated with an increased risk for NET, but if somebody with a NET tumor had somatic testing or genomic testing that showed a B-R-C-A or a BRCA mutation, there's a chance that that's actually germline, that it's in the healthy cells, and that that predisposes for other risks unrelated to NET tumors. And so, your clinicians are also partially doing a check to say, "this genetic change in your tumor could actually be something that's hereditary or runs in the family." And that is part of the workup.

So that is a thing that can be identified, but we typically don't talk about it as often. I think it's also worth noting that there are some genes that we see in both genetic/hereditary and tumor worlds that aren't as important. So B-R-C-A BRACA is an example where we say, "Yes, if we see that in a tumor, we know that somebody needs germline genetic testing," but there are other genes that we might look at in a tumor, and we know are very common genes to be mutated in tumors that are very rare to be mutated in the germline healthy cells. And so we partner often behind the scenes with providers who might say, "Hey, can you take a look at this somatic test?" A lot of places will have molecular tumor boards where they'll look at genetic and genomic testing to do an assessment. And part of our role can also be to look at somatic testing, tumor testing, and determine if there's any need for germline testing based on that.

Lisa Yen 35:10

Yeah. So, it's complicated, because you can have a gene that shows up in the tumor that may also be familiar. Oh, this tends to show up in the DNA, but it doesn't necessarily mean the same thing. Or it could.

Samantha Greenberg, PhD 35:21
Correct and every gene is a little bit different. And so, part of what we have done as genetic counselors, as the genomic testing has evolved over time, is start to get better at how we translate between them and how we support your care team in thinking about navigating all sides of genomic testing.

Lisa Yen 35:37
Well, perhaps a question that may come next is, is there one test for both, both genetic and genomic, and how do patients know if they're getting the right test?

Samantha Greenberg, PhD 35:46
That's a tough question. The answer is yes, there are companies that offer both tests that they will simultaneously order a germline genetic test and a somatic genomic test through the same company at the same time. Every clinician and every care team usually has a preference or a place they use, and so it's hard to say, you know, I think it would be challenging for a patient to walk in and be like, I want this joint thing, if the provider is really used to ordering the two separately, but they can both be done. And I think the question is, then, what is the right test? So, I just talked about genes. When we do genetic testing, we're not looking at all 20,000 genes. In a germline test for hereditary items, we're looking at anywhere from 10 to 40, depending on the type of tumor and what we're looking at. You know, 10 to 40 genes associated with NET. Now, when I'm thinking about individuals with breast or other cancers, I'm looking at a different set of 20 to 25. And so, I'd say it's unlikely that a care team is going to come in and be like, "I'm going to order a breast cancer panel for a NET patient." We have NET panels. We have broader panels. So, if somebody had a NET and a breast cancer in the family, we have testing panels that test 70 plus genes to look at both sets of genes.

And so, I do think one of the challenges in this area is there is a little bit of an inherent trust to make sure that the right genes are getting tested for. It is not the patient's responsibility to go and look up every single gene and make sure that it's associated. But I do think there are some very specific questions that you can ask to assess what's happening. So, when someone references genetic, genomic, NGS, et cetera, you can ask things like, "Is this looking at my tumor, or is this looking at the healthy cells?"

There's another type of testing we didn't talk about as much, where it's a blood sample, and they can identify a small percentage of tumor cells in someone's general blood sample, and they can use that

for genomic testing. And so, asking, "What are they testing on? Is it my healthy cells? Are they looking for cancer cells in my blood sample. Are they looking at my tumor?" Can start to give you a sense of is this germline or somatic. You can ask if they're testing for all of the genes associated with NET. They should be, but those can be some of the questions to help make sure that you're getting the right test. I don't think there's necessarily like a wrong test. It's very unlikely that we would see somebody ordering something totally unrelated, but I think that those are some of the questions that patients can start to ask to get the answers they need to feel comfortable that the provider is ordering the right thing for them.

The other thing that I would just add really quickly is that, as you start to get those answers, then you can ask for the thing you haven't heard. So, if you heard, "We're going to do a test of the healthy cells, and we're going to look for the cancer cells in this blood sample, and we're going to look at the tumor." If someone says, "Oh, we're only going to look at the tumor," then you can say, "Is there any reason to do genetic testing to see if I have a hereditary risk in my healthy cells that led me here," and allow that conversation to happen with your provider. If you had the liquid biopsy, so the blood test that has a small portion of cancer cells inside, you could say, "Is there a benefit in looking at the tumor?"

As a patient, you have the autonomy to ask any question you want. It is up to us as providers to give those explanations and be able to have those conversations, and we should be able to have those conversations about why we're doing one and not the other. There are a million reasons to have one and not the other, or two out of the three, or none of the three. If there isn't enough sample, and the tumor is not metastatic, so you're not going to see it in the blood sample, and it's a tumor type with no other family history, that person may not need any genetic or genomic testing. But it never hurts to ask.

Lisa Yen 39:32
This is helpful to have the questions and also clarity on what it is that is out there: testing the tumor, testing our healthy cells, and how to go about having a conversation around this.

So, could you walk us through what a consultation with a genetic counselor looks like? How does that process work? Who's referring to you? Do you assign homework or preparation before the appointment, and then what happens during the visit?

Samantha Greenberg, PhD 39:56
So, every clinic is a little bit different. A lot of cancer centers will send a little bit of homework in advance, mostly because when you come in, we're going to ask questions about your family history. And so, some clinics will ask for your family history in advance. It allows us to paint a picture of what's going on in the family, and they have a little bit more information going into it. If you think about all

your other processes, you want your providers to have looked at your charts ahead of time. You want them to have that information. And so sometimes we will ask people to fill out family history in advance, to give us a little bit more preparation. And if there's any additional work we need to do, that we can do it in advance.

That being said, family history is a challenging thing to sometimes acquire. And so sometimes people need a few weeks to talk to individuals and get that information, and some people just may not have that information. So either way, that's about all the information we have people bring in. If someone in the family has had genetic testing, we encourage people to bring that into a session as well.

And then during the session, we're going to do a variety of things: medical and family history intake. Some of that we'll get from the chart. Some of that will have additional questions. When we think about specific risks, there may be unique questions that we're going to ask, different from another clinician, because we want to very specifically assess for a specific condition. So, we referenced von Hippel-Lindau in my introduction. It is associated with some pancreatic NETs, but also pheochromocytoma, and that's a perfect example. We're going to ask about eye tumors, brain tumors, spine tumors, called hemangioblastomas that no one has probably ever asked about before. But we want to make sure that if there is a consideration of von Hippel-Lindau, that we've done our assessment. We've done our due diligence. We know if you and or family members have these other tumors that aren't NET-related but might be related to a broader condition.

Samantha Greenberg, PhD 41:40
And then we're just going to talk. I mean, that's really all a genetic counseling session is, is a decent amount of talking. But we're going to walk through, depending on your level of knowledge, where we start and where we end. So, I just gave the explanation of genes to you and things being added, missing, misspelled. We're going to have that same conversation with certain patients. And other patients are going to say, "We've done some genomic testing. I understand the premise. I want to understand how this impacts me." And we're going to talk about the types of test results and what happens in those test results. And some are going to come in and say, "Listen, I'm doing this. I don't care about it for me. I only want information for my family." And that's what we're going to talk about. Let's talk about what the test results mean for family. Let's talk about, if your family is at increased risk, that they should be doing screening proactively.

And so, depending on what the person is coming in for, what their level of knowledge is, what their level of educational interest is. Some people want to nerd out for the whole time, and some people want to get in get out, like, let's get this thing done. And we can be pretty flexible in that process. The process typically ends then, not for everyone, but for a lot of people with a genetic test. This can be done via a blood or saliva sample, although some of the technology is a little bit better with a blood

sample. Like I said, everything does NGS, but there's some extra layers when we have blood sample that we have a little bit more genetic material to be able to study besides a saliva sample, but both are possible. We'll order that testing. We'll consent. We'll walk through insurance processes, who to contact for billing questions, et cetera. And then when that test result comes back in three to four weeks, then we'll disclose that test. Most will do that over the phone, via my chart, et cetera. And so, it's typically just you come in for one visit, and then we're all set. Although if we identify a mutation, something that puts someone at increased risk, we're likely to have additional follow up. So that's kind of the before, during and after. And our goal is to really be a support in the entire genetic testing process.

Lisa Yen 43:30
Yeah, that's really helpful. I know that when my husband went through it the first time, more than 10 years ago, the paperwork was quite thorough and involved. It was like 12 pages and very thorough questions in terms of who had what in all different members of the family and took quite a bit of time to think through and prepare for the appointment.

Samantha Greenberg, PhD 43:50
Yeah, that's part of why we do it in advance. I think when people come in, they haven't done that, and then we get to, like, the third or fourth family member. And I often joke, "We didn't tell you there was going to be a quiz," but that's kind of how it feels. We're asking a lot of questions, questions you may have never talked with your family about.

As someone who was diagnosed with cancer about six years ago, I hadn't taken a family history of my family, and it caused me to dive deeper to assess what I needed in terms of genetic testing. And what was interesting about that process is that what I learned is that the things I'd been told were actually not entirely correct. Then when we went down the rabbit hole and we talked to this family member and then this family member, that there was some difference there.

And so that ability to have time is part of the reason that we often ask patients to do it in advance because I think it feels stressful sometimes, and it also feels different than anything else you're used to in a visit. And so, people just aren't as used to it, which is why we like to prepare them that we'll either be taking the family history or that it's helpful if they can provide it in advance.

Lisa Yen 44:47
Yeah, and that takes time and a thorough conversation. I think one thing that you said that's a little enlightening: A lot of times, we don't know. We don't know until you go through it what a genetic test involves. And the word "genetic test" almost implies there's one test, so I'm just going to go and get a

test. And so, what is the reason for all of this questioning? And what you said about you're not testing every single gene; you need to figure out which genes to test.

Samantha Greenberg, PhD 45:14
Correct. There are some specialties of genetics where someone will come in and they will look at all the genes, or a very, very large portion of it. But in the cancer setting, and in the tumor setting, we're typically looking at a targeted set of genes.

And the other piece of this that we don't talk about as much is insurance and coverage and guidelines. And there is no current benefit to testing you for 20,000 things if you have the personal history of a NET. There is benefit in testing you for 10 to 30 things. And so, making sure that we test for the right people at the right time, for the right thing, is kind of part of our job, and something that we really strive to make sure we're doing, which is why we're asking these questions. Because to your point, a genetic test looks very different for each individual patient that comes in based on their needs and their personal and family history.

Lisa Yen 45:59
So you want to make sure to be thorough and get the right test for the right patient, and to have that test covered by insurance.

Samantha Greenberg, PhD
Yeah.

Lisa Yen 46:07
So, say you've met with a person, you get the results back. What then happens if, unfortunately, the tests are positive? How do you guide patients, families, children through that information?

Samantha Greenberg, PhD 46:19
So how we guide patients and families through it, I think you're going to hear a common theme, "it depends." But I think that in general, when the results are positive, we know that one of three or up to three things are likely going to happen. There could be an impact to treatment or management of what's currently going on. So, there are some people with tumors, NETs, et cetera, that we say, "Hey, because of this diagnosis, this is going to shift how we think about treatment." That is the primary focus for somebody who's in the middle of that.

If somebody has had genetic testing after that process and they're positive, then we might need to think about being proactive and making sure we do early identification for other cancer risks. So, if I have a paraganglioma, pheochromocytoma, I have an increased risk for a second one, I need to make

sure I'm doing full body imaging every few years. And I'm going to do that in addition to the follow up from my tumor care.

And then the last piece is for families. So, a majority of conditions in the cancer and tumor space are what we call autosomal dominant, which means that there's a 50/50, chance for all first-degree relatives to have that same genetic change or mutation that we see in the person that we've done the initial testing on.

So now we need to go through and test all of our immediate family and start to branch out. We call it **cascade testing**, where we essentially start with a family member is closest to you, and then we keep testing until we get a negative. Once we get a negative test result, we know there isn't a genetic mutation or a change to pass on to another family member, but until we get there, we need to assess everyone in in that immediate family and ballooning out to make sure that we've identified anyone that's at increased risk for tumors, so that we can do that early detection and surveillance for them as well.

Lisa Yen 47:59
That's helpful. I mean, what does it mean for me now also is key. Like, what does it mean in terms of my treatment or surveillance and the plan moving forward? So helpful questions to keep in mind, as well as, of course, what it means for offspring and family members.

What if the results are negative or inconclusive? How accurate are they? And can there be any false positive, negatives?

Samantha Greenberg, PhD 48:22
This is a really good question. So the answer is, of the genes that we test for in a genetic test, the accuracy is very good. We typically do not see false negatives or false positives in these settings. Because we need to make sure we get it right. There are some conditions people proactively remove organs. We don't want to do that and be wrong, and so the thresholds that we use in genetic testing are very rigorous to ensure that they're accurate.

At the same time, there's a lot that we don't know about the genetics of cancer, tumors, NET, you name it. And so, is it possible that there is a genetic change out there in a gene we haven't discovered and therefore are not testing for yet? Is there a chance that there is a, what we call a multifactorial explanation that puts this person at increased risk, and the testing is negative? Multifactorial, meaning, rather than there being one specific mutation, there's a combination of changes in the genome or the genetic code that puts somebody at increased risk. All of those things can be possible, and so we've essentially ruled out with a negative test result, and I'll talk about inconclusive in just a second, but

with a negative test result, we've essentially ruled out any increased risk from the genes that we tested for, but that doesn't include what we don't know about or could discover in the future, and so we always encourage patients to give us a call every few years.

I just got an email from a genetic counselor yesterday about a patient, and said, hey, they had this testing in 2022, they called to ask if there was a different type of test. This is my understanding. These are my thoughts. What do you think? And it was in the NET space. And I said, you're totally right. They've had as comprehensive of testing. There is a marginal benefit in doing a new set of testing, but if they can just check back in five years, we'll probably be in a different place.

And so, those are the kinds of things you can see over time and over the last decade, even. Every three to five to ten years, it depends on how often. Over the last 20 years we've had some kind of seismic jump. We can't predict what that will be. All we can do for negative tests is recommend people keep checking in to see if there's any updated testing that they should do.

Lisa Yen 50:34
Yeah, that's helpful. When my husband was diagnosed 10 years ago, that was the last thing that the genetic counselor said that stuck with us. She said, "Give me a call back in five years, because we need to talk again. Things change." So we did. We put on a calendar. It's hard to think forward that I'm going to be around still in five years. What are we going to be doing? But yeah, five years later, we touched base, and she said, "Yeah, there have been changes. Let's run some more tests." So you said, three to five years? How often should patients return? Should they be contacting you? Should they get a referral?

Samantha Greenberg, PhD 51:04
Once you've seen a genetic counselor? We typically, and I don't want to speak for all clinics, it's typically reasonable to just reach back out to that person. If they're not there, somebody else can likely talk with you and just see, do we need to start the process again? Do we come back as a return visit? Every clinic is going to have their own policy process, et cetera. We say every few years. So, two to three. I think every five is also reasonable. I think it just comes down to the time, balance, effort, et cetera. I think we see changes closer to every five plus years than every two to three. And at the same time, some people think about this a lot, and so if you're someone who thinks about it a lot, I don't think it hurts to reach out every few years, but I think it's just helpful to be aware that every place is going to have its own preference. Every center is going to have its own recommendation. In most of the places I've worked it's been about three years.

Lisa Yen 51:54

So, this field keeps evolving, and it's helpful to remember that just like we as people evolve the field of medicine, the field of genetics also evolves.

Samantha Greenberg, PhD
Yes.

Lisa Yen 52:06
And that's a good thing, so hopefully that helps us as well.

With our tests, some things come up with V-U-S. What is this **V-U-S, variance of unknown significance** and what does it mean for patients?

Samantha Greenberg, PhD 52:16
So, V-U-S is sometimes I've recently heard them called VUS's. I do not call them that, so I will be calling them the V-U-S's, but in case you hear that, just so you know, apparently, it's a thing. But variants of uncertain or unknown significance, VUS for both are essentially genetic changes that were uncertain about their impact. So, we have millions of genetic changes in our body that make us different from one another, and not all of them impact our health. Most of them just make us different from one another. An uncertain or V-U-S essentially says we found a genetic change, and we don't know if this puts you at increased risk for tumors and NET, et cetera. Or if this is just something that makes you you. And because, as I mentioned, our thresholds are very strict, we don't want to be wrong, and so we keep a very high threshold of what becomes a positive or a negative, and if we're not certain, it goes in that VUS category.

Now because of that, we've done a lot of research and over 90% of the time, those uncertain results become negative because we have significantly more changes in our body that make us us then impact our health and put us at increased risk. And we see that play out 10 plus years into this, that's fairly consistent. So, we treat of VUS as a negative, because what we don't want to do is over screen, over monitor, tell you that you're at increased risk for something, and now you get your organs removed, and you never needed that. Especially when over 90% of the time it's going to be a negative.

And so, we presume that VUS's are going to be negative, that they do not impact clinical management, that there is no risk to family. And in the case, this is why it's also inconclusive and accuracy is a little bit challenging, because there is less than 10% of people with VUS's that might get an upgrade that might become a tumor risk related mutation, or what we call a pathogenic variant, formally. And so, I think sometimes people can feel like the test is inaccurate. We didn't know about this. Down the road, this VUS got upgraded, and we didn't do anything about it. In general, we have to make the decision

that we think is best for the broader population with the data that we have, and there are always going to be exceptions to that rule.

And so, in general, the tests are really accurate. We are testing for the right things. And at the same time, genetics is not black and white, and this VUS category is one that says, in general, it's negative, we're going to treat it as such, and if it ends up being in that rarer category, we're going to help you manage that when it happens.

Lisa Yen 54:43
That's a really helpful explanation. I think this can be really confusing, as it can pop up on many reports.

What about environmental exposures? Can hereditary mutations ever be caused by environmental exposures like toxins?

Samantha Greenberg, PhD 54:57
Not typically. So most hereditary conditions have been passed for generations. One of the things we see when we talked about the counseling side is sometimes people will feel guilty or blame or "I didn't know I passed it on." You know, "I feel terrible that I did this." And we didn't even know about it decades ago, let alone multiple generations ago. And so, we see almost all of these hereditary conditions passed from generation to generation. They've been around for a very long time, and in very, very rare scenarios, are what we call **de novo or brand-new** mutations. When those pop up, we typically don't associate them with environments or toxins or any of these things. And broadly, when we think about cancer, we think about environment, lifestyle and genetics, and they're three independent components that all contribute to a broader risk. But in general, we don't believe that environment or toxins cause hereditary mutations.

Lisa Yen 55:48
I'd love to pick your brain about this as well. So, we've heard that there's an increasing incidence, so rising numbers in general, and prevalence of neuroendocrine cancers. But just in general, it's on the rise. Why do you, as a genetic counselor, think that there's more and more neuroendocrine cancer now?

Samantha Greenberg, PhD 56:06
I am going to default to what some of the experts say, because I really do believe it. I think we are better at detecting. We are better at differentiating. So, when we think about, I made the reference to my family history. I always thought my grandmother had an ovarian cancer, and as I dove deep and started to hear some various words, I was like, "Oh no, she had this gynecological very unique cancer

that wasn't quite what I would call ovarian cancer." We are better at that than we were 30 plus years ago when my grandmother was diagnosed with that cancer. And so, we see a rise because we're better at naming it, we're better at detecting it, and I think we're generally getting a lot better at listening and believing and going through this process.

And so, I think when you think about our ability to identify and go through that process, then makes us better, and we identify more. And then we have to struggle with, are there really more, or were we just not finding them all to start? And I think anything beyond those thoughts are a little bit outside of what I would say, the scope of genetic counseling. But I do think that, in general, to your point, we're seeing a rise in early, younger cancers, and we're seeing a rise in certain cancer types. And so, we have a lot of work still to do to figure out is this because we're better at finding, detecting, et cetera, or is there something truly causing that increased risk?

Lisa Yen 57:30
Thanks for your insight in this, and I think we'll end with this. What is the best way for someone to find a genetic counselor who's the right fit for them, and do they need to be someone who really knows or understand or understand neuroendocrine?

Samantha Greenberg, PhD 57:41
This is going to be a little bit controversial, but I think the answer is, because the rise of NET is new in the genetic space, everyone will have seen a few and likely has seen a few patients here and there. But not even myself, I wouldn't even identify as a NET genetic counselor. There are not enough patients for me to see in those settings, and so I end up seeing patients across all different types of indications with a specialty, research-wise, in the NET space.

And so, I want to say that the right person for you is not actually somebody that says, "Oh, I've seen a million NET patients." If you meet one of those people, please email me and let me know. I'd love to meet them too, but it's just not as common. It's not something that we see as often. And so, you're going to find people that have that experience. They use these guidelines to get to where they need to be and to order the right genetic testing. But it's unlikely that you're going to find a NET expert like we have in some of our physician teams. That being said, my favorite place to find a genetic counselor is **findageneticcounselor.com**. Our national organization actually makes it quite easy. You can determine telehealth or in person. You put in your zip code, and then you select the specialty to be cancer, and it will generate a bunch of genetic counselors in your area. But it will also start to give you a sense of which hospitals have genetic counselors. Is there one at my center? Should I request somewhere else you mentioned earlier, the PheoParaAlliance designation for Center of Excellence, that is not for all net, but it is for Pheo Para. And so that gives you a sense that those centers likely see a higher volume of patients and are a little bit more familiar in those spaces. And so that can be a place to look all of

those sites for von Hippel Lindau or pheo para, both which are associated with NET tumors. Both of those sites require genetics and genetic counselors to be a part of the specialized care team. And so any of those approved centers you would know have the right resources that you need and could get you to the right expert.

But the last piece of that question is, how do I find the right genetic counselor for me? And I think two things are true. One, there is a quote unquote type for genetic counselors. And at the same time, our field has done an immense amount of work to break the mold that there is only one type of genetic counselor and that we have work to do to make sure that our workforce reflects the patients that we serve. And the right genetic counselor for you can be something like "I want to be seen. I want to call this center, and whoever they give me, I trust in this clinic and this hospital and this place, or I have found a center of excellence, or whatever it may be." But I think the other piece of this, and I do this for all of my providers, is to look and search and get a sense of whether there is a specific person that you might want to see. Is there something that you want to have a shared identity with? Is there something that you want to see in their profile that tells you that they'd be a good fit? For some people, there is, and for others there isn't. And so, we are not yet to a point, I think, like physicians, that you can go and just find the perfect genetic counselor for you. But I think if you are someone who is looking for someone very specific, then you can look up the genetic counselors via findageneticcounselor.com, one. Or two, look for centers that you know have some certifications in conditions that are associated with NET to give you a little bit more reassurance.

Lisa Yen 1:01:01
Thank you for some of those practical websites and tools and tips and tricks on how to find someone who's the right fit, and just a bigger picture understanding of how this all plays in.

Well, I think that's it for today's episode. I really, really want to thank you for all that you do for neuroendocrine cancer patients and their loved ones, for all you do to move this field forward. I know we've talked about your clinical care and you teaching and training other people, including med students. So, thank you for raising awareness and education in this field and also in the field of research, because that also helps move the field forward.

Samantha Greenberg, PhD 1:01:40
It was so exciting to chat with you, Lisa. I think one of the things that I love the most is really the balance of all the things and then getting a chance to be able to talk to the people that are actually the most impacted by this. I tell my students that the thing I love the most as I started my career was learning things in the research world and then being able to tell patients about what we've learned and where we've come. And so, I appreciate the opportunity to chat about that today.

Lisa Yen 1:01:03
Well, we really appreciate it. I always learn a lot talking to you, and I love how you really make this topic understandable. This is a really complex topic, and it can be really hard to understand. I get the terms confused. So, I really appreciate how you make this easy to understand, and now we have something that we can go back to and listen to again. Thank you so much for all you do and for your passion for this field.

Samantha Greenberg, PhD 1:02:28
Of course.

Lisa Yen 1:02:29
And for our listeners. We hope this conversation empowers you and your loved ones and you feel more informed and supported in your journey. So, thank you so much again, and we hope to see you again.

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